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Oxford Regional Training Course in Clinical Psychology

Doctorate in Clinical Psychology

The role of coping strategies in people who have psoriasis: an investigation and pilot intervention.

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ABSTRACT

This project consisted of a two pronged investigation into the role of coping strategies in psoriasis - a chronic, relapsing skin condition associated with impoverished quality of life and substantial psychological distress. The first study examined the relative influence of coping strategies on sufferers' subjective disability and psychological distress. The second study explored the efficacy of a pilot group intervention based on the format of Coping Effectiveness Training.

Study one utilised the theory of Appraisal and Coping (Lazarus & Folkman, 1984) to investigate the role of coping strategies in mediating subjective disability and psychological distress in 89 psoriasis sufferers. Empirical definitions of adaptive and maladaptive coping strategies were used to categorise coping. Maladaptive coping strategies, in particular venting emotions and mental disengagement, were significantly associated with both subjective disability and psychological distress, accounting for a greater proportion of the variance on these measures than age, gender or duration of psoriasis. Adaptive coping strategies were not inversely associated with the outcome measures.

Study two piloted a group based intervention derived from Coping Effectiveness Training - a structured problem focused group - with a self selected community sample of 16 psoriasis sufferers. While the intervention did not yield significant changes on outcome measures relative to the control group, there was a trend for a reduction in subjective disability. Participant feedback suggested that the intervention was felt to be useful and that specific coping techniques had been acquired as a result of the intervention.

Implications are discussed in terms of the roles of coping strategies and the use of structured group interventions in psoriasis, and suggestions for future research are outlined.

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I INTRODUCTION: OVERVIEW

The aims of this project were to investigate the coping strategies mediating subjective disability and psychological distress in psoriasis and to carry out a pilot intervention based on Coping Effectiveness Training.

The project is divided into two studies which were undertaken concurrently and represent an investigation into coping in psoriasis which is not known to have been carried out before with this population.

Study one is the systematic investigation of the mediating role of coping strategies in subjective disability and psychological distress in psoriasis. Study two is the group based intervention.

The introduction is composed as follows:

Part 2 - Medical information about psoriasis

Part 3 - Review of psychological factors in psoriasis and the factors predicting subjective disability and psychological distress.

Part 4 - Outline of theory of stress and coping, and development of Coping Effectiveness Training.

Part 5 - Aims of studies one and two.

2 PSORIASIS: MEDICAL INFORMATION

2.1 Epidemiology and prevalence

Psoriasis is an incurable, chronic, relapsing skin condition affecting 1% to 3% of the population. Men and women are equally affected, with a peak age of onset between 10 years and 30 years of age (Venables 1994). Psoriasis may occur from birth; up to 10% of sufferers develop the condition before the age of 10 years (Roenigk & Maibach, 1985).

The most frequently affected sites of the body are the scalp, elbow and trunk, although any area of the body may be affected. Several morphological types of psoriasis have been identified, which vary in clinical presentation and have been linked to different causes.

The most common form is plaque psoriasis which appears as raised red patches of skin covered with silvery scales. The individual lesions may merge together and can cover the entire body. Guttate psoriasis has the appearance of a rash and often develops following respiratory infections, streptococcal pharyngitis and viral flu. Pustular Palmar-plantar psoriasis - painful pustules on palms of hands and soles of feet - often occurs with fever and is also associated with withdrawal of steroids. Nail changes are common in psoriasis: yellowing and splitting may occur on some or all fingernails. Arthritis is also associated with psoriasis in approximately 6% of people with psoriasis and most commonly affects the hand joints. While these types of psoriasis are not life threatening, generalised pustular psoriasis and erythrodermic psoriasis are serious illnesses requiring hospital admission (Roenigk & Maibach, 1985) .

The prevalence of psoriasis decreases with age in the population. Within an individual, psoriasis may become more widespread throughout the body. Psoriasis typically follows a relapsing and remitting course: around 40% of patients experience remission lasting

from one to 54 years. In up to 30% of cases, spontaneous remission may occur without treatment, the cause of which is unknown (Roenigk & Maibach, 1985).

2.2 Aetiology

Psoriasis results from an acceleration of the normal process of skin replacement. A skin cell normally matures in 21 to 40 days, reaching the surface layer where a constant shedding of dead cells in the form of scales takes place. In psoriatic cells, this process occurs in two to three days and cells accumulate in visible layers. No single cause for psoriasis has been identified and it is likely that many factors are involved. There is a genetic susceptibility - with 35% of sufferers having a family occurrence. Early onset is most associated with familial factors. Many other factors such as climate, infections, hormonal changes, surgical trauma to the skin, certain drugs such as lithium, and psychological stress in the form of negative life events have been linked to an outbreak or relapse (Keinan, Segal, Gal, Brenner, 1995; Roenigk & Maibach, 1985).

2.3 Measures of severity

Objective measures use dermatologist ratings of psoriasis area and severity at different body sites (Roenigk & Maibach, 1985). Patient reported measures of severity, such as degree of itch, pain, discomfort, are also used. (McHenry & Doherty, 1992).

2.4 Medical effects and treatments

Apart from the disfiguring of the skin, sufferers may also experience extreme discomfort or pain, pruritus, and bleeding. Arthritis may cause additional difficulties with joint pain and immobility. Side effects from treatments may also be severe. Psoriasis is managed

using a combination of topical steroid creams, coal and wood tar derivatives, systemic treatments including chemotherapy, and ultra-violet light treatment - which requires hospital attendance.

Coal and wood tar derivatives come in the form of ointments, gels and bath solutions. Skin irritation, or acne may result. Corticosteroids are widely used, possible side effects including further skin complications such as allergic contact dermatitis. Use of creams and ointments are messy and time consuming and often requires several administrations over the course of a day. For severe psoriasis, ultra violet phototherapy and / or systemically administered medications are used, a common one being the antimetabolic drug methotrexate. Side effects may include headaches, fatigue, dizziness, gastrointestinal problems, depression and liver disease. Phototherapy, (UVB or PUVA) normally requires 20 to 30 treatments, three times weekly (Roenigk & Maibach, 1985) .

2.5 Summary

Psoriasis is a chronic, relapsing skin condition affecting 1% to 3% of the population. Severity, course, and age of onset may vary greatly between individuals. Psoriasis itself is not curable and can be disabling, painful and itchy. It is managed with a combination of topical treatments, and in severe cases with systemic drugs and phototherapy, which have potentially severe side effects. In addition, 6% of individuals suffer from psoriatic arthritis. There is no single known cause, although a genetic predisposition exists. Periods of relapse have been linked, among other factors such as surgical trauma and certain medications, to the experience of negative life events.

3 IMPACT ON QUALITY OF LIFE

"Because the disease is rarely fatal, its psychological impact may receive inadequate attention; the patient may ultimately feel like a medical nuisance, resistant to cure."

(Weinstein, 1984, page 513).

3.1 Psychological aspects of the condition

Quality of life refers to the overall subjective impact of a condition on the sufferers physical, psychological and social life. Until recently there was a relative lack of attention paid to the impact of psoriasis on overall quality of life (McKenna & Stern, 1997). Early research into psychological aspects of psoriasis were dominated by "futile searches for the 'psoriatic personality'" (Weinstein, 1984 page 509), in attempts to implicate underlying personality traits, or emotional disturbance, as causative factors in the disease onset (Ginsburg & Link, 1993; Weinstein, 1984). Such suggestions seem to serve to show the extent of public hostility towards sufferers of the condition, highlighting that sufferers not only have psoriasis to deal with, but the attitudes of those around them (Ginsburg & Link, 1993).

More recently, research has focused on two areas; the role of psychological factors, particularly stressful events, in exacerbating the condition, and the psychosocial aspects of living with psoriasis itself (Weinstein, 1984).

Several studies have sought to demonstrate a direct link between experience of stressful life events and subsequent flare up of psoriasis through retrospective surveys or use of diaries (King & Wilson, 1991). While self report methodology leaves findings open to

question, there has been a consensus from sufferers in a number of surveys endorsing stress as a factor in exacerbating their condition. In a community survey, 37% of respondents believed that recent stressful events precipitated an acute phase of psoriasis (Nevit & Hutchinson, 1996). The immune system has been proposed as a pathway through which stress may influence the condition, as has been suggested in HIV (Antoni, 1997). Thus a feedback loop may be initiated, with psoriasis itself acting as a stressor, triggering further flares (Ginsburg & Link, 1993).

Considering the chronic, unpredictable course of psoriasis, lack of a cure and its visibility and associated pain and discomfort, it is not surprising that the impact on quality of life may be substantial. Development of psoriasis-specific measures of subjective disability and distress have enabled psychosocial factors to be assessed in greater detail: emotional distress, social and occupational functioning, and self concept are the main areas which research surveys have addressed.

3.1.1 Emotional distress

There have been a number of surveys of both community and inpatient populations documenting emotional distress in the form of worry, despair, elevated rates of depression and anxiety (Dooley & Finlay, 1990; Ginsburg & Link, 1989; McKenna & Stern, 1997), and low overall perception of quality of life (O'Neill & Kelly, 1996). In a review, Ginsburg (1995) reported clinical rates of depression in a third of dermatology inpatients with psoriasis and in 15% of outpatients with psoriasis when a standard measure of depression was used. Most studies are cross sectional which may not take account of the variability in distress due to psoriasis over time. Fried et al (1995)

developed a self report questionnaire to discover the type and degree of psychosocial impairment present during acute flares of psoriasis. Nearly half of their sample of 64 outpatients reported moderate or extreme depression during flares, which is consistent with findings relating flare up to despair (Ginsburg & Link, 1989). Fried et al's study also reported significant (45% of respondents) psychological consequences of having the diagnosis of psoriasis itself, irrespective of current state of the skin. In the largest longitudinal study found in the literature, McKenna & Stern (1997) followed up over one thousand patients who had been seen for phototherapy treatment in 1979. Symptoms of depression and anxiety were self reported by 22%, and the psychological dimensions were reported to be the most affected compared to physical and social. A strong positive correlation has also been found between pruritus, depression and anxiety, pruritus being independent of severity (Gupta & Gupta et al 1994). Elevated rates of suicidal ideation have also been reported relative to the normal population; Gupta & Schork et al (1993) found that 10% of a mixed sample of inpatients and outpatients expressed a wish to be dead, while 5% admitted to active suicidal plans. In their study, depression was linked to self rated psoriasis severity.

3.1.2 Social and occupational functioning

There is empirical evidence for substantial social distress and impairment in areas of interpersonal relationships, work and social activities. It seems that well established relationships may be relatively unaffected and provide a primary source of support (Koo, 1996) while new relationships are hard to form: 67% of a community sample claimed their lives had been adversely affected by psoriasis, including difficulties

forming new social relationships and restriction of activities (McHenry & Doherty, 1992). Psoriasis may also affect sexual relationships in 30% to 70% of people, both due to direct - presence of genital psoriasis - and indirect - depression, social avoidance - factors (Gupta & Gupta, 1997).

Psoriasis clearly affects many sufferers ability to work. For half of the patients in McKenna & Stern's study (1997), who were not working, the reasons cited for not working were psoriasis or psoriatic arthritis. Similarly, Finlay & Coles (1995) found that one third of their sample attributed not working to psoriasis, and 60% took over 26 days leave during the year for treatment.

Avoidance of social situations is commonly reported in the literature. Ramsay & O'Reagan (1988) and Ginsburg & Link (1989) reported that over two thirds of their samples avoided common social activities, such as swimming, sunbathing, playing sports and visiting the hairdresser. Of particular concern, 11% to 15% of sufferers have admitted to avoiding leaving their own homes altogether, while 11% believed they would avoid having children in case they too developed psoriasis (Fried et al, 1995; Ramsay & O'Reagan 1988) . These patterns of avoidance were unrelated to severity of psoriasis (although the whole sample represented the more severe end of the spectrum of sufferers). In the fifteen year follow up study, 14% reported interference in normal social activities (McKenna & Stern, 1997), the notably lower figure possibly relating to the random nature of the follow up - regardless of whether patients were currently symptomatic.

3.1.3 Self concept

The visibility of a skin condition "attacks the very identity of the individual" (Ginsburg 1995, page 793), being central to that individual's self perception and experience in the social world. Embarrassment has been rated by patients as the "worst thing" about psoriasis since the early surveys were undertaken (Savin, 1970). In addition to the inherent difficulties in living with psoriasis, other opportunities for enhancing self esteem, such as work and social activities, may also be restricted, putting the individual at increased risk of negative self concept (Ginsburg & Link, 1993). The detrimental effect of psoriasis on aspects of self concept is being increasingly recognised and operationalised.

Self concept has been shown to be relatively stable in patients with psoriasis - not fluctuating with changes in condition severity: McKenna & Stern (1997) found that nearly 40% of the sample in their follow up study did not feel better about themselves despite physical improvement after intensive treatment, and they concluded that psoriasis has an "unremitting effect on the psyche" (page 393) for many people. So the impact on self concept has the potential to endure and persist after physical symptoms have lessened

Body image has been shown to be adversely affected in psoriasis sufferers in many studies; particularly frequently cited in surveys are "feeling unclean", and "physically unattractive" (McKenna & Stern 1997). Beliefs in others' negative perceptions were also commonly identified in surveys (Ramsay & O'Reagan, 1988) and have now been

incorporated into psoriasis-specific measures of stress (Fortune et al, 1997a; Gupta & Gupta, 1995a) or stigma (Ginsburg & Link, 1993).

The concept of stigma has been used to measure individuals' experiences of having psoriasis: stigma is defined as a biologic or social mark that sets a person off from others (Ginsburg and Link, 1989) and thus may leave a person susceptible to experiencing shame (Gilbert, 1997) . A wide variability in feelings of stigmatisation were reported (Ginsburg & Link, 1993), which were not predicted by extent or visibility of skin involvement. Ginsburg and Link (1993) found many examples of gross experiences of rejection (such as being asked to leave a public place) and related stigma to anticipation of rejection.

3.1.4 Summary

In addition to the distressing, painful and frequently debilitating nature of the symptoms, psoriasis has a substantial impact on psychosocial aspects of quality of life and has been associated with anxiety, depression, shame, social avoidance, reduced ability to work, and relationship and sexual difficulties. This review will now turn to the factors that have been found to mediate subjective disability and emotional distress.

3.2 Factors predicting subjective impact

Research has consistently shown that the subjective disability and emotional distress an individual suffers as a result of psoriasis is not a simple function of objective severity (Fortune et al, 1997a; Ginsburg & Link, 1989; McKenna & Stern, 1997; Root & Kent, 1994). Patient rated psoriasis severity has been shown to often correlate poorly with

doctor rated severity (Root & Kent, 1994), suggesting that what is important in a medical sense may not be the most salient or troubling aspect to the sufferer of the condition. Research has attempted to ascertain which factors predict psychosocial outcome.

Variables investigated in the literature can be broadly grouped into: demographic and psoriasis-specific variables; beliefs, behaviours and coping strategies.

3.2.1 Demographic and psoriasis-specific variables

Early research suggested that women were more likely than men to experience socially adverse effects of psoriasis due to the increased importance that society places on appearance of women (Gupta & Gupta, 1995b). However, recent surveys using measures of psoriasis related stress and self ratings of psoriasis severity (which have been found to correlate with measures of quality of life (Koo, 1996; Root & Kent, 1994)) found that there were no gender differences in overall impact on socialisation associated with psoriasis (Dooley & Finlay, 1990; O'Neill & Kelly, 1996), but that men were more afraid of losing their job (Gupta & Gupta, 1995b). Such different findings may reflect changed roles in society, or an increased willingness for men to admit to the difficulties caused by psoriasis. Significant differences have, however, been found with age in a number of studies; younger people being the most adversely affected by psoriasis (Gupta & Gupta, 1995b; McKenna & Stern, 1997). These authors attributed age differences to the increased importance of social stigma in the under 45 year age group, whereas for individuals over 45 years of age social networks are more likely to be established and stable. Other recent research supports these findings: Nevitt & Hutchinson (1996) also

failed to find gender differences in ratings of concern over the condition, but did find that concern was inversely related to age.

Being in employment has been found to be a buffer to psychological impact (Ginsburg & Link, 1993), possibly because of the opportunities it provides for social support and as a source of self esteem (Ginsburg & Link, 1993).

Specific psoriasis dimensions such as itchiness, extent of bleeding, visibility have also been investigated independent of overall severity. Perceived stigma was highly predicted by extent of bleeding of skin lesions (Ginsburg & Link, 1989) but not by extent or visibility of skin condition. Pruritus has been considered in a few studies and seems to have a large impact on quality of life and emotional distress: Fried et al (1995) found a strong correlation between itching, depression and anxiety. However, from a cross sectional design, it is impossible to tell the direction of causality. Gupta & Gupta et al (1994) found a strong correlation between depression and pruritus, and hypothesised that depression itself lowered the threshold for pruritus perception.

3.2.2 Beliefs, behaviours and coping strategies

In general, self rated severity has been found to correlate well with measures of impact on quality of life and general physical and mental health (Koo, 1996; Root & Kent, 1994) as well as with depression (Gupta & Schork et al, 1993). Self rated severity consists of an individual's perception of and beliefs about their condition. Scharloo et al (1998) found that impact of psoriasis on quality of life was significantly predicted by an individuals beliefs about their condition, in particular, a belief that they were suffering

from a serious illness which was uncontrollable and long lasting. The authors concluded that such beliefs have direct effects on functioning and psychological outcome. However this study did not measure psychological distress. Fortune et al (1997b), using a measure termed the psoriasis life stress inventory, identified specific beliefs and coping behaviours in patients with psoriasis which mediated the effect of the condition on subjective disability, being larger predictors than medical measures of severity. These were anticipatory-avoidance behaviour and beliefs or experience of others' negative evaluations.

Social support has been found to be a protective factor in psoriasis. Coping by seeking social support was significantly correlated with lower subjective disability (Scharloo et al, 1998). However, avoidance of social activities is common in people with psoriasis across the range of severity (Ramsay & O'Reagan, 1988). Rejection experiences were strongly correlated with perceived stigma, and highly related to despair (Ginsburg, 1995). Ginsburg & Link (1993) suggested that despair may influence psoriasis indirectly via failure to comply with treatment. Alcohol consumption was also significantly predicted by rejection experience and correlated strongly with despair (Ginsburg 1995).

3.2.3 Summary

The identification of key behaviours and beliefs that are associated with subjective disability and psychological outcome and mediate severity, especially avoidance and anticipation of rejection, indicate that these may be suitable for targeted intervention. Research has suggested that social support, avoidance and alcohol use influence the distress due to living with psoriasis.

4 STRESS AND COPING

4.1 Model of stress and coping

Lazarus and Folkman (1984) presented a transactional model of stress and coping which can serve as a theoretical framework for understanding individual interpretation of and response to psoriasis. According to their conceptual framework, perceived stress consists of three processes: primary appraisal - perception of threat; secondary appraisal - evaluating available responses to the threat; coping - carrying out a response. These processes do not necessarily take place sequentially, but operate in a continuous cycle of appraisal and reappraisal. Therefore perception of stress and response to it are represented as ongoing transactions between the individual and the environment.

Primary appraisal may result in an event being perceived as irrelevant, benign, or representing threat - loss, harm or challenge - where coping efforts need to be mobilised. The outcome of these processes are governed by complex interacting factors such as the degree of importance of threat or outcome, extent of helplessness and individual beliefs. However, the model emphasises that no single appraisal or coping response is inherently superior, rather that adaptive coping is a dynamic process, responsive to changing context.

A number of coping strategies may be used simultaneously with perceived changeability of stressor a crucial variable in predicting whether problem focused coping strategies, or emotion focused strategies such as acceptance and denial, are utilised. These two main coping strategies were distinguished by Lazarus and Folkman (1984), but Carver et al

(1989) believed that this distinction was too simple. As a result they devised a coping scale consisting of 15 subtypes of coping response.

This model of stress and coping emphasises the importance of a correct match between choice of coping strategy and changeability of stressor. Chronic medical conditions consist of both controllable and uncontrollable aspects (Antoni, 1997) and the model has been applied to coping with chronic illness and physical trauma. Kennedy et al (1995) conducted a cross sectional analysis of coping strategies used by patients six weeks and four to seven years following spinal cord injury. In both groups, quality of social support was negatively associated with psychological distress and acceptance was the most important predictor of better psychological adjustment. Behavioural disengagement, venting emotions, denial and alcohol / substance use were associated with worse psychological adjustment. In a longitudinal study, Kennedy et al (in press) found that these strategies emerged as significant predictors of anxiety and depression. Further, that they were consistent over time and predicted 67% of the variance on depression at one year follow up, indicating a causal link between coping strategies and emotional distress.

Coping strategies have also been investigated in populations of HIV positive men where disengagement, denial and alcohol use, and low treatment adherence were all significantly associated with poor immune system status and accelerated disease progression (Antoni, 1997; Chesney et al, 1996).

In chronic health conditions, which involve both controllable and uncontrollable stressors, adaptive coping - a good fit between choice of strategy and changeability of

stressor - has been empirically defined as consisting of: acceptance, active coping, positive reinterpretation, planning. Maladaptive coping - a poor fit between choice of strategy and stressor - has been empirically defined as behavioural and mental disengagement, denial, focusing on and venting emotions, alcohol and drug use (Antoni, 1997; Kennedy et al 1995). Kennedy et al (in press) found that more adaptive than maladaptive strategies were used overall in the sample of patients with spinal cord injury.

4.2 Summary

Adaptive coping has been defined as a good match between stressor and choice of coping strategy, maladaptive coping as a poor match between stressor and choice of coping strategy. Certain coping strategies in chronic health conditions involving both controllable and uncontrollable aspects have been empirically defined as adaptive and maladaptive:

Adaptive coping - acceptance, active coping, positive reinterpretation, planning.

Maladaptive coping - behavioural and mental disengagement, denial, focusing on and venting emotions, alcohol and drug use.

4.3 Development and application of Coping Effectiveness Training

Folkman et al (1991) developed a group based intervention termed Coping Effectiveness Training (CET) which was derived from the cognitive theory of stress and coping outlined in section 4.1. The focus of the intervention is on encouraging adaptive coping by matching choice of coping strategy to the extent to which stressful situations can be changed. The authors contrast their approach to stress management groups, which teach a range of general skills and do not emphasise the "fit" of coping strategy to specific

stressor (Chesney et al, 1996). The original version of their coping effectiveness intervention utilised two phases, training and maintenance. Six components constituted the intervention: appraisal of stressors, problem and emotion focused coping; fit between situation and coping strategy; use of social support; maintenance training and workbook exercises.

There is a developing body of empirical evidence for the effectiveness of CET as an intervention in chronic health conditions. Chesney et al (1996) conducted a randomised clinical trial of CET with HIV positive homosexual men. Two control groups were used, a general information group and a waiting list control. The study was completed by 84% of participants. The discontinuers were found to be significantly more anxious and less optimistic on initial measures than those who completed the study. Significant reductions in perceived stress and burnout, and significant increases in self efficacy, were found in CET relative to both control groups. Within group analyses found a reduction in anxiety and a trend for a reduction in depression. Antoni (1997) conducted a pilot study aimed at reducing maladaptive coping strategies of behavioural and mental disengagement and denial, and increasing adaptive strategies of active coping, planning and acceptance in a ten week cognitive-behavioural intervention for asymptomatic HIV positive homosexual men. They concluded that distress and depression were reduced.

In a recent controlled study of the application of CET to spinal cord injury, King and Kennedy (1999) found significantly greater decreases in depression and anxiety in the treatment group than the control group which were maintained at six week follow up. No significant changes in coping strategy were obtained, with the exception of

"acceptance", which decreased significantly in control group and was maintained in the treatment group.

Therefore there is evidence that CET may be an effective intervention in chronic health conditions in reducing levels of psychological distress.

4.4 Previous interventions for people with psoriasis

The mutual support and shared experiences that a group setting offers have long been recognised as valuable in a condition where stigma and isolation predominate (Logan 1985, cited in Burr & Gradwell 1996). The main function of support groups established for psoriasis sufferers therefore has been to increase social support and reduce isolation (Ginsburg, 1995). In these groups, some of which were initiated by nurses perceiving a need for such help for sufferers, members reported increased confidence and believed that it had been beneficial to share their feelings (Burr & Gradwell, 1996).

The few evaluated group based interventions in the literature can be generally subdivided into those concerned with the effect of psychological intervention on condition severity directly, and those interested in psychological outcome measures. Most interventions aimed at reducing severity of condition via the impact of stress on the condition have focused on techniques such as stress management, relaxation and guided imagery, either on an individual (Zachariae et al, 1996) or group (Keinan et al, 1996) basis. There are several case report examples of stress management alleviating the symptoms of rash in atopic dermatitis (Halford & Miller, 1992). Keinan et al (1995) explored the effects of relaxation and biofeedback groups on psoriasis severity, relative to a waiting list control

group. The group receiving relaxation and biofeedback self-reported greater symptomatic improvement relative to the same season of the previous year, but not relative to the start of treatment, than controls. The authors attributed these findings to the major seasonal fluctuation of psoriasis and concluded that combined relaxation and biofeedback may be an effective way to help to reduce the symptoms of psoriasis.

Of the studies focusing on psychological, as well as medical, outcome variables, few have used control groups. Ehlers et al (1995) drew attention to the lack of controlled studies in this area and provided an example of a well designed randomised controlled study of patients with atopic dermatitis. Patients were randomly allocated to one of five groups: education programme; relaxation; cognitive-behavioural intervention consisting of relaxation and training in problem solving and assertiveness, a combination group of education plus cognitive behavioural, and a control group receiving standard medical care. The groups consisted of 12 weekly sessions of one and a half hours and had between five to seven participants. Scores were compared on a range of measures of psychological well-being - depression, anxiety, atopic dermatitis related distress - as well as medical measures of skin severity. The group receiving education combined with cognitive behavioural intervention showed a significant decrease in anxiety at the end of treatment, sustained at one year follow up. There was also a reduction in frequency of catastrophising cognitions in all the treatment groups relative to the control group, and, at follow up, a significantly larger improvement in skin condition in the treatment groups.

Of the group based studies in psoriasis, only two could be found which attempted to use a control group. The most recent, Price et al (1991), used two weekly eight week groups

led by a clinical psychologist. Patients were randomly assigned either to treatment or control group. Fifteen patients were initially assigned to a group, of which 11 patients completed the groups, with 12 in the control group. Mean age was 46 years and mean duration of psoriasis 25 years. The group included relaxation, and discussion of aspects of the difficulties posed by psoriasis, and the effect on self concept and self esteem. Measures of depression, anxiety, self esteem, and social adjustment were taken pre and post intervention and at six month follow up. There was a significant group * time interaction effect for anxiety, the treatment group decreasing in anxiety scores, which was sustained at six month follow up. In Bremer Schulte et al's study (1985), a physician and patient trained together to facilitate 10 weekly two hour sessions (duo formula group treatment) focused on self care and stress management. Treatment groups consisted of seven members and there was a waiting list control of 14 members. A questionnaire was constructed concerning aspects of illness behaviour, shame, problem solving, assertiveness. The authors did not subject the results to ANOVA's but between group analyses of score changes showed significant decreases in illness behaviour, shame and shyness in the treatment group, along with increases in interactional skills and problem solving.

In addition, Abel et al (1990) reported on the content of an open ended non controlled weekly support group run for patients at a Psoriasis day care centre in the U.S.A., led by a psychiatrist. Common themes included loneliness and isolation, altered self-image, interpersonal relationship difficulties, changes in personal habits, career choice, medical concerns. Kang Seng et al (1997) reported on a non controlled pilot project in Singapore of seven sessions with a group of ten self selected psoriasis patients, either members of

the association or from the medical caseload. A structured format was used, including topics of understanding psoriasis, acceptance, anxiety and stress, daily hassles of psoriasis, medical aspects. In each session a case study fuelled discussion. No formal measures were used but a subjective questionnaire suggested that participants had found the group useful in increasing their knowledge and acceptance of the condition.

Despite the clear psychological impact of psoriasis, the potential benefits of group treatment, and the encouraging results from some studies undertaken, there is evidence that psoriasis patients are difficult to engage in psychological treatment approaches. Fortune et al (1998) investigated the reasons for poor uptake of a cognitive behavioural intervention programme at a tertiary psoriasis clinic: of 87 eligible patients, only 10% of those who were invited eventually took part in the programme. By comparing initial scores between those who subsequently took up the psychological programme and those who did not, they found significant differences on measures of beliefs about severe consequences of psoriasis, pathological worry and feelings of stigmatisation, with pathological worry best predicting non uptake of service in patients who initially agreed to participate.

4.5 Summary

Evidence from the few group interventions suggests their use in reducing emotional distress, particularly anxiety, and enhancing quality of life in patients with psoriasis. However to date there have been few controlled studies derived from a specific theoretical rationale and none which have aimed to match coping strategy to changeability of stressor, which would seem to be important in a fluctuating condition

consisting of controllable and uncontrollable aspects. There is evidence that psoriasis patients are a hard group to engage in group interventions, hindered perhaps by the very difficulties which such groups would attempt to address.

5 OUTLINE OF STUDIES

5.1 Outline of study one

5.1.1 Rationale

Psoriasis has been shown to have a clear impact on quality of life. The literature has identified several variables mediating the impact of psoriasis on subjective disability and psychological distress, in addition to medical severity. There is some evidence that these mediating factors may influence psoriasis, either directly, via proposed links with the immune system, or indirectly via changed behaviours. Research has suggested that behaviours and beliefs about the condition are important determinants of subjective disability (Fortune et al, 1997b, Scharloo et al, 1998) as are certain coping responses such as use of social support, seeking information and adhering to treatment regime. Other coping responses, such as use of alcohol and avoidance of activities, have been correlated with poorer outcome. In many surveys, however, specific coping strategies have not been assessed using standardised measures. Fortune et al (1997a, 1997b) found that subjective disability was strongly predicted by anticipatory-avoidance behaviours, and beliefs in, or experiences of, others' negative evaluations.

Folkman & Lazarus's theoretical framework has been used to identify specific coping strategies which have predicted variance in measures of psychological adjustment in other chronic health conditions. Psoriasis is recognised as a chronic condition which demands life time coping and adjustment, therefore the theory of appraisal and coping would seem to be a useful framework within which to conduct further research. It would be useful for further studies to employ standardised coping scales to investigate the

association between coping strategies and subjective disability and psychological distress in psoriasis.

5.1.2 Aims of study one

*** Explore the relationship between coping strategies, subjective disability and psychological distress in a community sample of adults with psoriasis.**

The four outcome variables used were subjective disability, psoriasis specific stress, anxiety and depression. Psoriasis specific stress was measured using the Psoriasis Life Stress Inventory and was defined as anticipatory-avoidance behaviour and beliefs in or experience of others' negative evaluations.

It was important to determine if the findings of Fortune et al (1997b) would apply to this sample, and to explore further the mediation of coping strategies. Fortune et al (1997b) had found that anticipatory-avoidance behaviour, and beliefs in, or experience of, others' negative evaluation, best accounted for the variance on a measure of subjective disability.

*** Investigate whether coping strategies are correlated with the other mediating variables of age, gender or duration of psoriasis.**

The role of age and gender factors in adjustment to psoriasis have received mixed evidence in the literature, and it may be that they reflect the employment of systematically different coping strategies which mediate the psychological impact of psoriasis.

*** Identify the coping strategies which could be addressed in a psychological intervention.**

The study aimed to determine whether the empirically defined adaptive and maladaptive strategies found in the other chronic health conditions also applied to psoriasis, and the extent of their influence on outcome variables.

5.1.3 Hypotheses

1) Subjective disability will be best predicted by anticipatory-avoidance behaviour and beliefs in others' negative evaluations, rather than by age, duration of psoriasis, gender, anxiety and depression.

2) Coping subscales will predict a significant proportion of the variance in the four outcome measures.

3) There will be an association between age, gender, duration of psoriasis and coping strategy.

4) Adaptive coping will be inversely related to scores on the four outcome measures.

5) Maladaptive coping will be positively related to scores on the four outcome measures.

5.2 Outline of Study two

5.2.1 Rationale

Conducted concurrently with study one, this pilot intervention intended to target specific coping behaviours and beliefs in psoriasis which have been suggested as mediating subjective disability and psychological distress. Coping Effectiveness Training offers a framework of a structured group based intervention based on a theoretical rationale, and has been shown to be successfully applied in other chronic health conditions. Of the psoriasis group programmes reviewed, the components of a structured, educational focus, use of relaxation, problem solving and assertiveness, are shared by the format of Coping Effectiveness Training, suggesting its appropriateness. However, no study yet seems to have addressed match of coping strategies specifically in interventions for people with psoriasis. It has been suggested that these coping strategies may be influential variables in both subjective disability and psychological distress. It therefore seemed appropriate to modify and pilot an intervention derived from Coping Effectiveness Training for this group.

5.2.2 Aims of study two

*** Investigate whether a community sample of psoriasis sufferers could be engaged to attend a weekly Coping Effectiveness Training group.**

*** Investigate whether the group improved the outcome on measures of subjective disability and psychological distress, and increased adaptive coping, relative to controls.**

*** Investigate whether the group was perceived to be useful by participants, particularly in enhancing coping with psoriasis and reducing emotional distress.**

The four outcome measures were subjective disability, psoriasis-specific stress, anxiety, depression.

5.2.3 Hypotheses

(hypotheses one to five refer to study one)

6) Treatment participants will show a significantly greater reduction on scores on the four outcome measures than controls.

7) Treatment participants will show a significantly greater increase in adaptive coping strategies (active coping, acceptance, positive reinterpretation, planning) than controls.

8) Treatment participants will evaluate the groups positively in terms of perceived usefulness, relevance and enhancement of coping ability.

II: METHOD

6.1 Participants

Participants were recruited from the dermatology outpatient clinic and through the local Psoriasis Association. All those who suffered from psoriasis and were between 16 and 70 years of age were considered eligible for the initial questionnaire survey. Patients were either known to have a diagnosis of psoriasis, if recruited through the clinic, or self reported a diagnosis of psoriasis, through the association. Patients needed to be able to understand and complete the questionnaires.

Participants for the intervention pilot group in study two were a self selected subset of those from study one, from either the clinic pool or the association pool, who were interested in attending a group, had the means of getting to the hospital site in the evening, and were not known to be receiving ongoing psychological treatment. These requirements excluded some people who had family or other evening commitments or, in some cases, no means of transport. The control group for study two were also composed of a subset of study one participants, matched as far as possible for age to the intervention group, who expressed a willingness to act as controls in the study. (Some had been interested in participating in the intervention, but were unable to attend). Study two had originally been planned as a randomised controlled study, but it was recognised early on that the sample size would not permit this, and recruitment was changed to inviting those who wished to attend.

6.2 Design

Study one was a cross sectional postal questionnaire design with outcome variables of Psoriasis Disability Index (PDI); Psoriasis Life Stress Inventory (PLSI); Anxiety (HAD); Depression (HAD) and independent variables of measures of coping strategy, age, gender, psoriasis duration.

Study two was a non randomised controlled pilot study comparing participants in the intervention group to the control group on the above range of outcome measures.

6.3 Measures

6.3.1 Demographic data

Information was requested on age, sex, duration of psoriasis, treatment currently receiving, marital and occupational status.

6.3.2 Psoriasis Disability Index (PDI) (Finlay, Khan, Luscombe, Salek 1990)

The subjective disability due to psoriasis was assessed using this fifteen item self report measure answered on a visual analogue scale graded from 0 to 6, ranging from "not at all" to "very much". The questions form five subsets; daily activities (five items), work or school (three items), personal relationships (two items), leisure (four items), treatment (one item). Patients are asked to consider how the disease has affected them in these areas over the previous month when completing the measures. The PDI score is calculated by summing the responses and provides an overall measure of subjective disability which can range from 0 to 90. A higher score indicates greater quality of life impairment.

The PDI has well established reliability, for example, test-retest reliability (Finlay & Kelly, 1987) and has been validated against the Sickness Impact Profile - a detailed general measure of the impact of disease - (Finlay, Khan, Luscombe, Salek 1990). Kent & Abadie (1993) factor analysed the scale and compared responses from individuals with psoriasis and other skin conditions. Their results showed that the items were effective in discriminating between psoriasis sufferers and patients with other skin conditions.

6.3.3 Psoriasis Life Stress Inventory (PLSI) (Gupta & Gupta 1995).

This fifteen item scale provides a rating of the recurrent stress associated with living with psoriasis. Each item is measured on a four point scale, a score of 0 indicating "not at all" and a score of 3 indicating "a great deal". The overall score provides a measure of psoriasis related stress which can range from 0 to 43. A score of greater than or equal to 10 is taken as high stress, less than 10 low stress. When completing the questionnaire, patients are instructed to consider their psoriasis related experiences over the last month. The scale was constructed from endorsements of 217 patients with a wide range of psoriasis severity. The scale has high internal reliability, Cronbach's alpha for all 15 items was 0.9, and good construct validity, with a direct correlation between PLSI score and patient self rating of psoriasis severity in different body regions.

Fortune, Main, O'Sullivan et al (1997a) subjected the scale to a factor analysis and identified two factors: stress due to anticipatory-avoidance coping behaviour, and to beliefs or experience of negative evaluation by others.

6.3.4 Hospital Anxiety and Depression Scale (HAD) Zigmond & Snaith (1983)

This 14 item self report scale is designed to be used in non psychiatric populations where physical illness may affect the scores on traditional measures of depression and anxiety. The questionnaire consists of two subscales, each of seven items, yielding a separate score for anxiety and depression. Questions are answered on a four point scale, a score of 0 indicating "not at all" and 3 indicating maximum agreement. Patients are requested to respond according to how they have been feeling in the previous week. The cut off for clinically significant levels of anxiety and depression can be taken as either 8 or 10. Eight indicates possible clinical levels of anxiety or depression, ten indicates probable clinical levels of anxiety or depression. Ten was used as cut off in the current study. The scale has been validated against interview ratings, and has good internal reliability (Zigmond & Snaith 1983).

6.3.5 COPE scale (Carver, Scheier, Weintraub (1989)

This is a 60 item self report measure of coping strategies. It is divided into 15 subscales, each consisting of 4 items, scored on a one to four point scale, with 1 representing "not used / hardly ever" and 4 representing "very frequently". The subscales are: active coping, planning, suppression of competing activities, restraint coping, seeking instrumental social support, seeking emotional social support, positive reinterpretation and growth, acceptance, religion, focus on and venting emotions, denial, behavioural disengagement, mental disengagement, use of alcohol / drugs, humour.

For each strategy, a score of between 4 and 16 may therefore be obtained. The COPE has well established psychometric properties (Carver et al 1989). The COPE may

either be used as a situational measure, coping with a specific situations or events, or as a dispositional measure. As psoriasis is chronic and relapsing, and the current state of psoriasis was not known, subjects were asked to respond according to how they believed they generally coped with psoriasis.

6.3.6 Participants evaluation of the intervention

A short questionnaire was designed by the researcher to ascertain how useful the intervention was perceived to be. Questions using a 0 to 5 visual analogue scale were devised on: whether the group was useful; whether participants' concerns were addressed; whether participants felt able to express their concerns in the group context; whether participants felt more able to cope with their condition. There was also space for general comments, a question on what was perceived to be most useful / least useful and whether any new or different coping strategies were going to be employed.

6.4 Procedure

6.4.1 Contact and liaison with nursing and dermatology staff

Following meetings with the consultant dermatologist in the early stages of this project, a file was established of all the referrals to the outpatient clinic who had a diagnosis of psoriasis, dating back the previous six months. This was updated as new referrals were added.

The researcher attended an outpatient clinic, workshadowing the consultant, to gain increased understanding of medical aspects of the condition and the type of concerns expressed. A room for the group meetings was arranged in the dermatology ward, a

setting familiar to some of the participants. Informal meetings with the nurses on the ward were held in order to discuss the project and receive suggestions.

6.4.2 Recruitment for study one

There were two sources of recruits: from the dermatology outpatient clinics and from the psoriasis association. These were both initiated to collect a sufficient pool of people for a group intervention to be feasible.

Clinic recruits: following ethical approval, everyone with a diagnosis of psoriasis who had received outpatient treatment within the previous six to eight months and who was between 16 years to 70 years of age, was contacted by post. An outline of the study was given, and a reply slip enclosed for those interested in hearing more to respond (Appendix 2). Those interested were requested to send the reply slip back in the prepaid envelope with their address and telephone number. Those who were not interested needed to take no action.

A post box for reply slips was also left in the dermatology outpatients reception area. Nurses gave out the explanatory sheets at the fortnightly clinics to those patients who had a diagnosis of psoriasis. Any patient who was interested in hearing more was requested to fill in the reply slip with their name and address and leave it in the post box.

Association recruits: the chairman of the local branch of the psoriasis association had been contacted by post and expressed his support and interest. The researcher attended a psoriasis association committee meeting and presented the project to the committee. The

study outline, a reply slip and stamped addressed envelope, were then sent out with the next association newsletter to all their registered members. A paragraph in the newsletter from the chairman endorsed the study. As a significant proportion of members of the association were also likely to be attending the dermatology outpatient clinics, recruits were also asked not to duplicate their response.

All mail for the researcher was addressed to the care of the consultant dermatologist. A tray in the dermatology secretary's room was established for the research mail.

All those who replied indicating that they were interested in hearing more were contacted by telephone by the researcher. A convenient time was arranged to discuss the study if the time telephoned was not convenient. In the telephone conversation, the proposed study, both the survey and the group, were outlined stressing that the study was concerned with understanding how people coped with living with psoriasis and the difficulties it presented for them. The intervention group was emphasised as one utilising a structured focus on coping and problem solving, and as a forum to share concerns and ideas with other sufferers. The call ended by discussing any questions or queries from the potential participant. Those who were willing to complete the questionnaires, initially whether or not interested in the group, were sent the questionnaires by post along with an information sheet and consent form, and stamped addressed envelope (Appendices 3,4 and 5). A contact teletelephone number was included. All questionnaires were coded to preserve anonymity.

6.4.3 Recruitment for study two

This was initiated once the first set of questionnaires had been received. Those who had expressed an interest in the intervention were then telephoned again, as had been outlined and agreed in the first telephone call. Optimum weekday evenings were sought from each person, and a consensus reached. Those unable to attend on the night selected were asked if they wished to wait for possible inclusion in a subsequent group, if still interested (three groups were run in total). The time interval between receipt of questionnaires and start of the group was between four and six weeks. If participants decided to join a later group, they were sent a repeat set of questionnaires a month before the start of the later group. For those not able to attend, they were asked if they would be willing to act as controls for the study and complete an additional set of the questionnaires once the first group had been completed.

Once the arrangements for the group intervention were finalised, the participants were again contacted by telephone and final details confirmed, including parking, directions, and the number of people in the group. It was also a time when any final queries or concerns could be raised with the researcher.

These telephone conversations enabled a relationship to be established between the researcher and participants before the start of the intervention, and for the researcher to gain some understanding of the specific concerns of various group members.

Those who had expressed a willingness to act as a control were sent the repeat questionnaires two months later along with a letter reminding them of the nature of the study (Appendix 6). A summary of the results was promised to those who indicated that

they would be interested in receiving this. In an attempt to match age range as far as possible when matching numbers in the treatment and control groups, the researcher excluded the oldest two participants who had been willing to be in the control group, although their first set of questionnaires were still used for analysis in study one.

The recruitment took place in two phases, the first phase consisted of the postal requests to outpatient sample, and the second phase the postal requests to the psoriasis association sample, although recruitment through attendance at the clinic was ongoing throughout this time. Intervention groups two and three were recruited using the same procedure as intervention group one, outlined above. As most of the hospital outpatients were approached first, the first intervention group consisted mainly of the hospital recruits while the second and third groups consisted mainly of the association recruits. However, there was some overlap due to discontinuers and some initial hospital recruits joining a later group if it was more convenient.

Those who failed to attend the groups or discontinued were still included in the overall sample for study one, as initial questionnaires were received before the intervention commenced.

6.4.4 Intervention groups

Each group was held on the same weekday night - Tuesday for the first two groups and Monday for the third - in the dermatology ward. The ward has beds for eight inpatients and so had nurses on duty during the time the groups were running. The groups were held in the day room in the ward. Handouts for each week were given. Those who had

missed a meeting were given the handouts the following week, with opportunity to discuss them.

6.5 Ethical considerations

6.5.1 Ethics approval

Ethics approval was sought and obtained from the local research ethics committee.

See Appendix 1.

6.5.2 Arrangements for distress

Participants in the group interventions were given the researcher's telephone number in case they were unhappy with any part of the group. The number of the dermatology ward was also given so that messages, for example, of people unable to attend, could be left. In addition, people were encouraged to contact their G.P. if it was felt that individual help would be of benefit. This was emphasised in the group in general and also discussed individually with one participant at the end of a group meeting. If a participant missed a group without leaving a message, they were contacted by the researcher to ensure that they were not left distressed as a result of a group, and to discuss whether they wished to continue. It was emphasised that they were free to withdraw from the study at any point. At the end of the groups, all participants were asked to provide feedback.

During the initial recruitment telephone calls, if it was felt that people were experiencing difficulties they were encouraged to seek help from their G.P.

6.6 Construction of the group programme

Theoretical information was available from published literature on the general content of other psoriasis interventions. Clinical information was obtained through the dermatologist and ward nurses at the outpatient clinic where the groups were to be held. Knowledge was also obtained from a psychologist experienced in working with people with psoriasis at a tertiary clinic. From these sources, ideas of the concerns relevant to patients with psoriasis were generated. Group material was also taken from other sources: problem solving (Hawton & Kirk, 1989); challenging thoughts and assumptions (Greenberger & Padesky, 1995); panic and anxiety (Clark, 1989); shame (Gilbert 1997); assertiveness (Powell, 1992). Following completion of a draft version, the proposed content was reviewed with the chairman of the local psoriasis association, himself a sufferer, to ensure that the final programme was appropriate to the concerns of psoriasis sufferers.

6.7 Content of the group programme

Following the format of King & Kennedy (1999) the group programme consisted of seven sessions of about 75 minutes, run weekly. Each session was structured and covered a particular theme, beginning with a review of the week before. Although structured, there was time in each group for group discussions around the themes raised. A more detailed summary of the intervention content can be found in Appendix 8.

Session 1: Concept of stress; typical reactions to it; living with psoriasis as a source of stress; introduction to appraisal and coping.

Session 2: Appraisal, identifying and breaking down problems; coping by changing the situation or by changing our reactions to the situation. Coping with psoriasis as one of multiple demands on resources, energy and time.

Session 3: Problem solving. Typical problem scenarios of awkward social situations, or experiences of rejection used to generate ideas and discussions.

Session 4: Emotional reactions, depression and anxiety. The cycle of panic and cognitive behavioural model of panic attacks. Link between thoughts, feelings and behaviour. List of behaviours which elevated self esteem, mood and confidence. Relaxation tapes issued to group participants.

Session 5: Negative assumptions. Focus on self concept, role of psoriasis in development of self concept. Shame and its role in psoriasis. Effects of assumptions on current thoughts and emotions ,and idea of challenging assumptions introduced.

Session 6: Coping with psoriasis. Commonly used strategies; differences due to age, culture, and gender. Importance of flexibility in fluctuating condition. Effects of maladaptive coping, in particular the cycle of withdrawal and avoidance.

Session 7: Use of social support and the difference between assertive, passive and aggressive modes of interaction. Practice of assertiveness skills and discussion of contexts which moderated their use.

III RESULTS: OVERVIEW OF DATA ANALYSIS

The analysis of results is divided into three sections. Section 7 presents the sample characteristics and representativeness. Section 8 presents the results for study one, and section 9 presents the results for study two.

The following analyses were conducted for each of the investigations.

Section 7 *Sample characteristics and representativeness:* The questionnaire measures all used equal interval scaling and consisted of subscales of at least four items, so provided a spread of data distribution. However, the further assumption for parametric t tests comparing means - that the population from which the sample is drawn has a normal distribution - could not be assumed for these variables. For this reason, non parametric, Mann-Whitney U tests were conducted on the data comparing two means. Where three means were to be compared, a Kruskal Wallis test was used.

Section 8 *Hypothesis one: Subjective disability will be best predicted by anticipatory-avoidance behaviour and beliefs in others' negative evaluations, rather than by age, duration of psoriasis, gender, anxiety and depression.*

Hypothesis two: Coping subscales will predict a significant proportion of the variance in the four outcome measures.

For the analyses of predicting variables a series of parametric stepwise multiple regressions were run. Concerns of the normality of the measurements do not apply for the regressions, but the assumption that the residuals are normally distributed was tested by conducting Kolmogorov-Smirnoff tests on each. All residuals were found to be normally

distributed. In addition scatter plots were undertaken of residuals against predicted values to test the assumption of constant variance. In all cases this assumption held.

Hypothesis three: There will be an association between age, gender, duration of psoriasis and coping strategy.

Hypothesis four: Adaptive coping will be inversely related to scores on the four outcome measures.

Hypothesis five: Maladaptive coping will be positively related to scores on the four outcome measures.

A series of parametric Pearson correlation coefficients were calculated on the variables.

The same assumptions applied as for multiple regressions.

In order to test for effects due to gender, where only two values are possible, non parametric Mann Whitney U tests were conducted, comparing the mean scores for males and females on outcome measures and coping strategies.

Section 9 *Hypothesis six: Treatment participants will show a significantly greater reduction on scores on the four outcome measures than controls*

Hypothesis seven: Treatment participants will show a significantly greater increase in adaptive coping strategies than controls

To test these hypotheses, a series of repeated measures ANOVA's were conducted.

While these also assume normality of measurements, they are robust to departures from normality. The number of ANOVA's conducted on the same data set - 15 subscales of the COPE and four outcome variables, increased the risk of a type one error.

Hypothesis eight: Treatment participants will evaluate the intervention group positively in terms of perceived usefulness, relevance, and enhancement of coping ability.

As the feedback questionnaire, constructed by the researcher, could not be assumed to fulfil the assumptions for parametric tests, non parametric Kendall's correlation coefficients were used to correlate the change in score on the outcome measures with subjective ratings on the feedback questionnaire.

RESULTS: SAMPLE CHARACTERISTICS AND REPRESENTATIVENESS

7.1 Demographic data

The participants were drawn from two sources, the Dermatology hospital outpatient clinic, both through a postal request and through attendance at the clinic, and by post through the Psoriasis Association (self help group). Response rates are shown for each of these sources, and for the whole sample.

7.1.1 Response rates

Table 1 gives the response rates for each stage in the recruitment. Initial overall response rates of 45% are comparable to other surveys for this population (Finlay & Coles 1995).

The slightly lower rate from the association may have been due to duplication - some people would also have been attending the dermatology clinic. The high response rates of 80% for questionnaire returns reflects the fact that contact had already been made with the respondents by telephone and questionnaires were only issued to the people who had agreed to receive them.

Table 1: Response rates

Sample	Total requests N	Replies N	Response rates %	Q'aires sent N	Q'aires received N	Response rates %
Clinic o/p	not known	19	n/a	19	12	63%
Clinic postal	118	51	43%	36	31	86%
Association	220	81	37%	56	46	82%
TOTAL	338	151	45%	111	89	80%

7.1.2 Sample Characteristics

Table 2 gives the mean age, duration of psoriasis and gender distribution for the sample.

A mean age of 49.7 years is slightly higher than for other studies in this population.

Psoriasis duration is similar, and the sex distribution is consistent with other studies

(Koo 1996; McHenry & Doherty 1992). Of the sample, 53.9% were employed, 42.7%

not in paid employment. 74.2% were married or living with a partner, 10.1% single,

7.8% divorced and 5.6% widowed. There was no occupational or marital status

information for two of the participants. In terms of treatment 10.1% were currently

having or had received phototherapy in the last month, 15.7% were taking systemic

medication 61.8% using topical creams / steroids, and 18% no treatment currently. Some

people were using a combination of treatments so the figures do not add to 100%.

Table 2: Gender distribution, means and standard deviations of age and psoriasis duration for clinic, association and whole sample.

	Clinic N = 43	Association N = 46	Whole sample N = 89
Age / yrs	48.7 (13.8)	50.9 (15.5)	49.7 (14.7)
Duration psoriasis / yrs	22.0 (16.1)	33.3 (17.2) **	28.1 (17.6)
Sex: Male	17	16	33
Female	26	30	56

** p<0.01

Non parametric Mann Whitney U tests were conducted to test for differences on the

above variables between the two sample sources. There were no significant age

differences, but duration of psoriasis was significantly longer in the association sample

than the clinic sample. Gender distribution was tested using a chi square analysis. There

were no significant gender differences.

7.1.3 Match between association and clinic samples

As participants were recruited from two different sources, tests were conducted on the mean scores on all the questionnaire measures to check whether the two sources could be combined into one sample for analysis. Table 3 gives the means and standard deviations for each questionnaire measure for both sources separately and the whole sample.

Table 3: Means and standard deviations of variables for association, clinic and whole sample.

	Clinic (N = 43)	Association (N = 46)	Whole sample (N = 89)
Subjective disability (PDI)	24.9 (21.2)	16.5 (16.5)	20.7 (19.3)
Psoriasis-stress (PLSI)	16.4 (12.0)	15.2 (10.2)	15.8 (11.1)
Anxiety (HAD)	8.1 (5.8)	5.7 (4.7)	6.9 (5.7)
Depression (HAD)	7.4 (4.1)	6.0 (4.3)	6.7 (4.2)
COPE SUBSCALES	(N = 42)	(N = 44)	(N = 86)
Restraint	8.0 (3.2)	8.2 (2.8)	8.1 (2.9)
Positive Reinterpretation	8.8 (3.3)	10.3 (3.3)	9.7 (4.4)
Active coping	10.0 (3.7)	10.5 (3.1)	10.3 (3.4)
Planning	9.1 (3.5)	10.3 (3.6)	9.8 (3.6)
Emotional social support	8.8 (3.1)	7.9 (3.4)	8.2 (3.2)
Instrumental social support	8.8 (3.6)	8.3 (3.4)	20.7 (19.2)
Suppress competing activities	7.9 (3.3)	8.2 (3.0)	8.1 (3.1)
Religion	6.7 (4.1)	6.4 (3.2)	6.5 (3.5)
Acceptance	11.4 (3.6)	11.9 (2.9)	11.7 (3.2)
Mental disengagement	7.5 (3.0)	7.4 (2.8)	7.4 (2.9)
Vent emotions	8.7 (4.3)	7.4 (3.0)	8.0 (3.6)
Behavioural disengagement	6.8 (3.4)	6.0 (2.0)	6.3 (2.7)
Denial	6.0 (2.5)	5.7 (2.1)	5.8 (2.3)
Alcohol	5.1 (2.5)	5.3 (2.9)	5.2 (2.7)
Humour	6.6 (2.6)	6.5 (2.9)	6.5 (2.8)

There were no significant differences between association and clinic samples on any of the above measures. They were therefore combined into a single sample for analysis.

7.1.4 Levels of clinically significant distress

The percentage of the sample suffering from clinically significant distress was evaluated, taking a score of greater than or equal to 10 as cut off for anxiety and depression, to indicate probable clinical levels, and 10 as indicating high stress on the psoriasis life stress inventory. The results are shown in Table 4.

Table 4: Levels of clinically significant distress

	Clinic		Association		Whole sample	
	N	%	N	%	N	%
Psoriasis-stress (PLSI)	24	55.8	31	67.4	55	62
Anxiety (HAD)	15	34.9	9	19.6	24	27
Depression (HAD)	13	30.2	11	23.9	24	27

Of the whole sample, 27% were significantly depressed and anxious (although the composition of individuals differed between the two measures). In addition, 62% were experiencing a high degree of distress related to their psoriasis. These figures were consistent with the research findings (McKenna & Stern 1997).

8 STUDY 1: DATA ANALYSIS

A series of stepwise multiple regressions were undertaken to determine the variables predicting subjective disability and emotional distress. In all the regressions that follow, checks were carried out that the assumptions of parametric tests held: Kolmogorov-Smirnoff to test that residuals were normally distributed; scatter plots of residuals against predicted values to ensure equal variance.

8.1 Predictors of subjective disability

Hypothesis 1: Subjective disability will be best predicted by anticipatory-avoidance behaviour and beliefs in others' negative evaluations rather than by age, duration of psoriasis, gender, anxiety and depression.

As a preliminary measure, a Pearson correlation matrix of the outcome and demographic variables suggested that these were all, except gender, significantly associated (to $p < 0.05$) with subjective disability: age ($r = -0.22$, $p < 0.05$); duration of psoriasis ($r = -0.21$, $p < 0.05$); psoriasis-stress ($r = 0.8$, $p < 0.01$); anxiety ($r = 0.49$, $p < 0.01$); depression ($r = 0.44$, $p < 0.01$). Gender not included in the correlation matrix as only two values were possible.

Two stepwise multiple regressions were performed with subjective disability as the dependent variable. All the other outcome measures, coping strategies and the above demographic variables were selected for inclusion in the regression analysis.

In the first regression, the measure of psoriasis-specific stress, which consists of anticipatory-avoidance behaviours, and beliefs in others' negative evaluation, was entered as a single variable, with one single overall score.

The best model contained three variables which were entered in the following order:

Psoriasis-specific stress accounting for 67% of the variance

($F=151.2$, $R^2 = 0.67$, $p<0.001$), venting emotions accounting for a further 4% of the variance ($F=89.5$, $R^2 = 0.71$, $p<0.001$) and gender a further 3% of the variance ($F=68.9$, $R^2 = 0.74$, $p<0.004$).

In the second regression, psoriasis-specific stress was split into the two factors of anticipatory-avoidance behaviour and beliefs in others' negative evaluations, using the factor solution of Fortune et al (1997a). In this model, behaviours accounted for most of the variance, 59% ($F=107.1$, $R^2 = 0.59$, $p<0.001$), venting emotions a further 9% of the variance ($F=76.1$, $R^2 = 0.68$, $p<0.001$), gender a further 3% ($F=57.3$, $R^2 = 0.71$, $p<0.003$) with beliefs in others' negative evaluation accounting for an additional 3% ($F=49.7$, $R^2 = 0.74$, $p<0.005$).

Therefore the variance is most strongly predicted by anticipatory-avoidance behaviour as found in the analysis of Fortune et al (1997b). Beliefs in others' negative evaluations accounted for an additional 3% after venting emotions and gender.

Hypothesis one was partly confirmed. Overall, anticipatory-avoidance behaviours and beliefs in others' negative evaluations accounted for 67% of the variance on subjective disability - the single best predictor. The behaviour component of psoriasis-specific stress

alone best predicted subjective disability. Beliefs in others’ negative evaluations added a small, but significant independent contribution which was not as important in accounting for the variance in subjective disability as venting emotions or gender.

8.2 Coping strategies

Hypothesis 2: Coping strategies will predict a significant proportion of the variance on the four outcome measures.

The preliminary Pearson correlation coefficients of demographic variables in Table 5 show that in this sample age was significantly inversely correlated with anxiety, subjective disability, and psoriasis-specific stress. Duration of psoriasis was significantly correlated with anxiety, and with subjective disability, but not with psoriasis specific stress or depression. These were therefore entered into the appropriate regression analyses.

Table 5: Pearson correlation matrix: age, duration of psoriasis and outcome variables.

	Age	Psoriasis Duration
Subjective disability (PDI)	-0.219*	-0.214*
Psoriasis-stress (PLSI)	-0.264*	-0.177
Anxiety (HAD)	-0.300**	-.0289**
Depression (HAD)	-0.145	-.0184

* p<0.05, **p<0.01

To conduct the regression analyses, the outcome measures were each selected in turn as dependent variables while the other three were excluded from the analysis. This was in order to eliminate the strong reciprocal relationship between the outcome variables themselves, and to allow the influence of coping strategies and age, gender and psoriasis duration to be examined.

8.2.1 Subjective disability as the dependent variable.

A three variable model accounted for most of the variance, with the variables entered in the following order: Venting emotions 36% ($F=41.2$; $R^2 = 0.36$, $p<0.001$); Alcohol 4% ($F=24.1$, $R^2 = 0.40$, $p<0.05$); Mental disengagement 3% ($F=18.0$, $R^2 = 0.43$, $p<0.05$).

8.2.2 Psoriasis-specific stress as the dependent variable.

A three variable model accounted for most of the variance, with the variables entered in the following order: Venting emotions 28% ($F=28.3$, $R^2 = 0.28$, $p<0.002$); Alcohol 6% ($F=18.5$, $R^2 = 0.34$, $p<0.02$); Mental disengagement 4% ($F=14.7$, $R^2 = 0.38$, $p<0.05$).

8.2.3 Anxiety as the dependent variable

A five variable model accounted for most of the variance, with the variables entered in the following order: Venting emotions 48% ($F=66.8$, $R^2 = 0.48$, $p<0.001$); Duration of psoriasis 6% ($F=42.0$, $R^2 = 0.54$; $p<0.005$); Disengagement 4% ($F=33.0$, $R^2 = 0.58$, $p<0.001$); Positive reinterpretation 2% ($F=26.9$, $R^2 = 0.60$, $p<0.02$); Religion 3% ($F=23.9$, $R^2 = 0.63$, $p<0.05$).

8.2.4 Depression as the dependent variable

A two variable model accounted for most of the variance, with the variables entered in the following order: Venting emotions 24% ($F=23.1$, $R^2 = 0.24$, $P<0.001$); Alcohol 6% ($F=15.5$, $R^2 = 0.30$, $p<0.05$).

Therefore a significant proportion of the variance on all the outcome measures were predicted by use of certain coping strategies and hypothesis two can be confirmed.

8.3 Correlations

Hypothesis 3: There will be an association between age, psoriasis duration and gender and coping strategy.

Table 5 shows that in this sample age is inversely related to subjective disability and psychological distress. A correlation matrix of the different coping strategies, age, and duration of psoriasis is presented in Table 6. In order to determine any influence of gender, Mann Whitney U tests were conducted.

Table 6: Pearson correlation matrix: age, psoriasis duration and coping strategies

Coping Strategy	Age	Psoriasis Duration
Restraint	-0.27*	-0.058
Positive Reinterpretation	-0.24*	0.005
Active coping	-0.01	-0.01
Planning	-0.03	-0.15
Emotional social support	-0.185	-0.18
Instrumental social support	-0.091	-0.141
Suppression of competing activities	-0.236*	-0.248*
Religion	0.052	0.063
Acceptance	-0.030	0.272*
Mental disengagement	-0.191	-0.200
Venting emotions	-0.360**	-0.208
Behavioural disengagement	-0.275*	0.076
Denial	-0.230*	0.07
Alcohol	-0.286*	0.019
Humour	-0.338**	0.049

* p < 0.05, **p < 0.01

Gender differences were assessed conducting Mann Whitney U tests for male versus female on all the above variables. No significant differences emerged on the outcome measures. There was one significant difference with the use of coping strategies: women

scored significantly higher on the subscale of venting emotions than men ($U=439$, $p<0.05$).

Psoriasis duration only correlated significantly with two coping strategies; suppression of competing activities and acceptance. There was a negative correlation with suppression of competing activities, suggesting that as people have psoriasis for longer, they are less likely to stop other activities in order to focus on the psoriasis. There was a positive correlation between acceptance and psoriasis duration, but not with age itself.

Age was significantly inversely related to eight coping strategies: younger people showing more use of maladaptive coping strategies such as denial, disengagement, venting emotions and alcohol use. More use of positive reinterpretation, an adaptive strategy, however, also occurred in younger people.

Therefore hypothesis three was confirmed: age was associated with greater use of coping strategies, and particularly with maladaptive strategies. Duration of psoriasis was associated with acceptance. Being female was associated with venting emotions - a maladaptive strategy.

8.4 Association between outcome measures and coping strategies.

Hypothesis 4: Adaptive coping - acceptance, positive reinterpretation, planning, active coping - will be inversely related to scores on the four outcome measures.

A series of Pearson’s correlation coefficients were conducted to determine the relationship between the four outcome variables and use of different coping strategies.

Table 7 gives the values of the correlation coefficients with significance indicated.

Table 7: Pearson correlation matrix: outcome measures and coping strategies.

Coping strategy	Depression	Anxiety	PDI	PLSI
Restraint	0.259*	0.381**	0.246*	0.236*
Positive reinterpretation	-0.028	0.048	0.130	0.131
Active coping	0.067	0.197	0.251*	0.232*
Planning	0.023	0.183	0.208	0.136
Emotional social support	0.119	0.335*	0.161	0.118
Instrumental social support	0.147	0.299**	0.179	0.202
Suppress other activities	0.272*	0.390**	0.358**	0.339**
Religion	0.153	0.184	0.055	-0.029
Acceptance	0.054	0.037	0.022	0.002
Mental disengage	0.384**	0.554**	0.471**	0.463**
Venting emotions	0.501**	0.697**	0.601**	0.529**
Behavioural disengagement	0.374**	0.384**	0.318**	0.340**
Denial	0.310**	0.251*	0.345**	0.270*
Alcohol	0.330**	0.173	0.317**	0.349**
Humour	-0.059	-0.055	0.013	-0.025

* p < 0.05, ** p < 0.01

There were no significant correlations between acceptance, positive reinterpretation, or planning and any of the four outcome measures. Active coping was significantly positively related to subjective disability and psoriasis-specific stress, indicating that those who coped actively reported greater disability and distress as a result of psoriasis. Suppression of competing activities was also significantly associated with all four outcome measures.

Therefore the results do not confirm hypothesis four.

Hypothesis 5: Maladaptive coping - behavioural disengagement, mental disengagement, denial, venting emotions, and alcohol / drug use - will be positively related to scores on the four outcome measures.

Table 7 also gives the correlations of the maladaptive coping strategies and the outcome measures. All these coping strategies except alcohol / drug use were highly significantly correlated with all four measures of psychological distress and subjective disability.

Alcohol / drug use was highly significantly correlated with all measures except anxiety.

Therefore the coping strategies defined as maladaptive are related to elevated psychological distress in this sample and hypothesis five was confirmed.

9 STUDY 2 - PILOT INTERVENTION - DATA ANALYSIS

9.1 Attendance

Table 8 gives the attendance figures for the number of participants attending the groups, those who failed to attend, discontinuers, and the number of sessions that each attended.

The total numbers of people completing the groups were six in the first group, four in the second group, six in the third group. There were 13 discontinuers: nine people had agreed to attend the first group, 10 people to groups two and three.

Table 8 gives the numbers completing and discontinuing the three groups.

Table 8: Numbers and percentages completing and discontinuing the three intervention groups

	Did not attend N	1 to 3 sessions N	Completed N	Percentage completing %
Group 1	2	1	6	66.7
Group 2	1	5	4	40
Group 3	1	3	6	60
Total	4	9	16	55

Of those who completed the groups, the number of sessions attended ranged from five to seven. The total number of people attending each session varied between four and nine with the exception of session five in group two which had only two attenders.

Reasons given for discontinuing included work or other evening commitments, difficulty with transport, or illness. In addition, one person felt that she had no need of the group, one person felt that he did not relate to the other group members, and one person found that hearing others' concerns made her feel more depressed.

Therefore, in terms of the aim of the pilot intervention, it was shown to be possible to engage a sample of community psoriasis sufferers to attend an evening group.

9.2 Sample characteristics

Table 9 gives the demographic data for whether in paid employment, marital status and whether currently receiving medical treatment for psoriasis. This included phototherapy, systemic therapy and topical treatment.

Table 9: Numbers and percentages in intervention and control groups: paid employment, marital status and medical treatment for psoriasis.

	Paid work	Not paid	+ partner	single	divorced	widowed	Current treatment
Treatment	13 (81.2%)	3 (18.8%)	14 (87.5%)	1 (6.3%)	-	1 (6.3%)	13 (81.2%)
Control	9 (56.2%)	7 (43.8%)	10 (62.5%)	3 (18.8%)	2 (12.5%)	1 (6.3%)	15 (93.7 %)

For both groups, more than half were in paid employment, and the majority were married or living with a partner. Eighty one percent of the treatment group and 93.7% of the control group were receiving medical treatment for their psoriasis at the time of the study. This covered a range from phototherapy and systemic treatment to topical treatment.

9.3 Match of treatment and control groups

Table 10 gives the data for age, duration of psoriasis and gender for the treatment, control group and the discontinuers. Table 11 gives the initial scores on the four outcome variables for treatment, controls and discontinuers. In order to test whether the three groups differed significantly on these variables, a series of non parametric Kruskal Wallis tests were conducted.

Table 10: Gender distribution, means and standard deviations for age and psoriasis duration in treatment group, controls and discontinuers.

	Treatment N = 16	Control N = 16	Discontinuers N = 13	H	p
Age /yrs	47.4 (10.2)	50.5 (16.4)	49.4 (14.7)	0.79	NS
Duration psoriasis / yrs.	24.0 (14.2)	28.0 (16.7)	26.3 (19.5)	0.20	NS
Gender M	5	9	3	3.8 (Chi square)	NS
F	11	7	10		

There were no significant differences in the mean ages or psoriasis duration between the three groups. Gender distribution was tested using a chi square analysis. There were no significant differences in gender distribution.

Table 11: Initial scores on outcome measures: means and standard deviations for treatment group, controls and discontinuers.

	Treatment N = 16	Control N = 16	Discontinuers N = 13	Chi square	p
Subjective disability (PDI)	25.1 (20.8)	23.0 (24.5)	25.9 (19.0)	0.571	NS
Psoriasis-stress (PLSI)	18.8 (11.2)	14.6 (12.1)	17.7 (12.3)	1.871	NS
Anxiety (HAD)	9.8 (5.9)	7.9 (4.8)	6.6 (6.0)	2.748	NS
Depression (HAD)	7.8 (4.6)	7.1 (3.6)	7.1 (4.9)	0.735	NS

There were no significant differences in the initial scores between the three groups. Therefore the treatment and control groups were reasonably matched, and the discontinuers did not differ significantly on initial scores from those who completed the groups.

9.4 Outcome of group intervention

In order to evaluate the changes in outcome variables due to the intervention, a series of repeated measures ANOVAs were conducted using the outcome variables and coping strategies.

Hypothesis 6: Treatment participants will show a significantly greater reduction in scores on the four outcome measures than controls.

Table 12 gives the mean scores before and after the intervention for the treatment and control groups on the four outcome measures. The F value stated in the table gives the value for the group * time interaction effect. Degrees of freedom for the F statistic were all 1,30. Individual changes in scores are given in Appendix 9.

Table 12: Outcome measures: means, standard deviations and significance before and after the intervention for treatment and control groups

	Treatment		Control		F	p
	pre	post	pre	post		
Subjectivedisab (PDI)	25.1 (20.8)	16.1 (17.5)	23.0 (24.5)	21.3 (21.5)	2.9	0.09
Psoriasis-stress (PLSI)	18.8 11.2)	15.8 (9.7)	14.6 (12.1)	16.1 (21.2)	1.5	NS
Anxiety (HAD)	9.8 (5.9)	8.7 (4.4)	7.9 (4.8)	8.4 (4.0)	1.1	NS
Depression (HAD)	7.8 (4.6)	7.3 (4.4)	7.1 (3.6)	8.1 (4.1)	1.3	NS

* p < 0.05

There were no significant group * time interaction effects for any of the outcome measures, although there was a trend for a greater reduction in subjective disability (PDI) in the treatment than in the control group.

As the ANOVAs assume normal distribution, non parametric within-group and between group analyses using the Wilcoxon Signed Ranks test and Mann Whitney U test respectively were also employed as a precaution. For the within-group analyses there was

one significant result - a significant reduction in subjective disability from pre to post intervention in the treatment group ($Z=-2.5$, $p=0.01$). There were no significant between-group differences on any post intervention outcome measures.

Figures 1 to 4 give the mean scores in the treatment and control groups before and after the intervention. Although no significant group*time interaction effects were found, the figures show that change was in the direction of score decrease solely in the treatment group on all four measures.

Fig 1: Anxiety

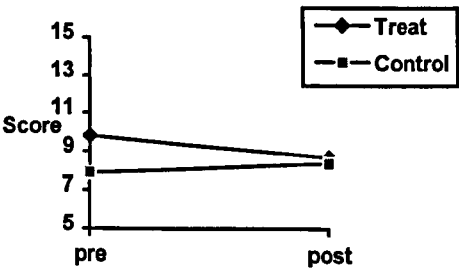


Fig 2: Subjective Disability

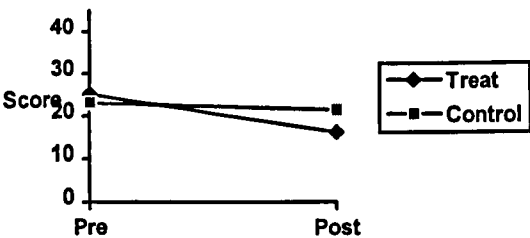


Fig 3: Depression

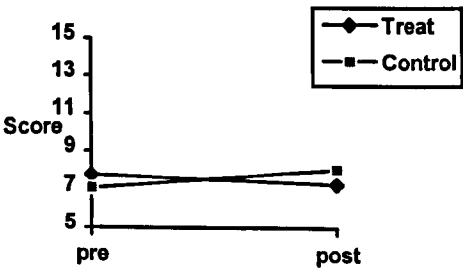
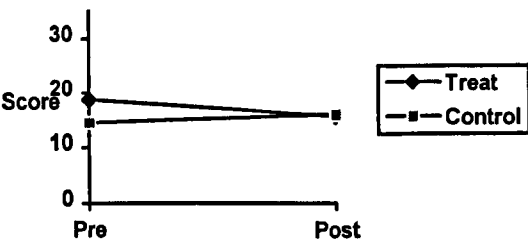


Fig 4: Psoriasis Stress



No significant reduction in treatment relative to control group occurred on any of the four outcome measures, therefore hypothesis six is not confirmed.

Hypothesis 7: Treatment participants will show a significantly greater increase in adaptive coping strategies than controls.

Table 13 gives the means and standard deviations of scores on the 15 coping subscales for the treatment and controls before and after intervention. F gives the value of the group*time interaction effect. One repeat coping questionnaire in the control group had only been partially completed and was excluded from this analysis, leaving N=15 in the control group. Degrees of freedom for the F statistic were all 1,29.

Table 13: Coping strategies: means, standard deviations and significance before and after intervention for the treatment and control groups

COPE	Treatment		Control		F	p
	pre	post	pre	post		
Restraint	9.3 (3.1)	9.6 (3.4)	7.3 (2.9)	6.5 (1.9)	1.6	NS
Positive reinterp	10.2 (2.9)	10.7 (2.9)	7.5 (3.2)	7.5 (2.9)	0.4	NS
Active Plan	11.1 (3.5)	11.3 (3.0)	9.2 (3.2)	9.1 (2.9)	0.0	NS
Emotional support	11.4 (3.2)	12.1 (3.4)	7.6 (3.0)	7.7 (3.0)	0.4	NS
Instrumental support	9.2 (2.9)	9.6 (3.5)	8.1 (2.8)	7.5 (2.7)	2.1	NS
Suppress other acts	9.4 (3.6)	9.8 (3.7)	7.6 (2.7)	8.3 (3.0)	0.1	NS
Religion	9.2 (3.5)	9.5 (2.3)	7.1 (3.0)	7.2 (2.7)	0.1	NS
Accept	5.3 (2.1)	6.4 (3.6)	6.1 (3.8)	6.2 (3.7)	1.2	NS
Mental disengage	11.7 (3.6)	11.9 (2.5)	11.3 (3.5)	9.6 (2.9)	1.728	NS
Vent emotions	8.3 (2.3)	8.1 (2.2)	6.8 (3.3)	8.3 (3.3)	4.2	0.05 *
Behave. disengage	9.7 (3.7)	9.7 (3.5)	7.3 (3.6)	7.6 (3.2)	0.005	NS
Denial	6.8 (3.4)	7.1 (2.6)	6.6 (3.2)	6.5 (3.0)	0.3	NS
Alcohol	5.9 (2.5)	6.8 (3.0)	5.7 (2.0)	6.1 (3.3)	0.2	NS
Humour	4.1 (0.3)	4.1 (0.3)	4.8 (1.6)	5.8 (3.1)	4.3	0.05 *
	5.9 (2.1)	7.9 (3.0)	6.4 (2.1)	6.4 (1.9)	6.2	0.05 *

* p < 0.05 df=1, error df=29

There were no significant group * time interaction effects for any of the adaptive coping strategies, although there was a slight trend for an increase in the seeking of emotional social support in the treatment group. There was a significant group * time interaction

effect at the $p < 0.05$ level for use of mental disengagement, alcohol and humour. It can be seen that scores on mental disengagement and use of alcohol / drugs stayed similar in the treatment group pre and post intervention , and showed an increase in the control group over the study time period. There was an increase in the use of humour in the treatment group over the period of the study.

As many of the scores on the adaptive coping methods were already high pre treatment, there may have been a ceiling effect on the results.

Therefore treatment participants did not show a significantly greater increase in adaptive coping strategies relative to controls and hypothesis seven was not confirmed.

9.5 Participant evaluation

Hypothesis 8: participants will evaluate the groups positively in terms of perceived usefulness, relevance and enhancement of coping ability.

Table 14 gives the mean ratings of the participants on the feedback questionnaire which was constructed using a five point scale from 0 to 5.

Table 14: Feedback ratings

	Min	Max	Mean
Usefulness	2	5	4.25 (1.00)
Relevance	3	5	4.13 (0.89)
Group context	4	5	4.56 (0.51)
Effect on ability to cope	2	5	3.56 (1.03)

Most participants rated the group highly in terms of its usefulness, relevance to concerns, group context (enabling members to express their concerns), and effects on ability to cope. The highest rated was the ability to express concerns in the group context, the lowest rated was the effect on perceived ability to cope, although this was still rated

highly by all but two of the participants. The same participant rated the groups low for usefulness and for effect on ability to cope.

In order to determine the match between participant evaluation of group and the objective measures, the above four questions from the feedback form were correlated with the change in scores on the standardised measures. Difference was calculated by subtracting the initial scores from the post intervention scores so that a positive outcome score indicates a drop in psychological distress. These differences were then intercorrelated with the measures of participant rating, using non parametric correlations.

Table 15: Correlation matrix: participant ratings with change in outcome measures

	Usefulness	Relevance to concerns	Group context	Increase in ability to cope
Subjective disability change	0.04	0.13	0.15	0.05
Psoriasis-stress change	0.21	0.21	0.07	0.18
Anxiety change	0.18	0.09	0.27	0.42*
Depression change	0.01	-0.06	0.08	0.13

* p < 0.05

There was one significant correlation: increase in perceived ability to cope correlated significantly with decrease in anxiety.

9.6 Individual change.

While clinically significant change was not assessed in this study, the numbers of participants above and below clinical cut off for anxiety, depression and psoriasis specific stress were considered in the treatment and control groups, in case the intervention was differentially effective with those whose scores are above the clinical cut off initially.

Using cut off score of greater than or equal to 10 on the anxiety and depression measures (indicating probable depression and anxiety), and greater than or equal to 10 on the measure of psoriasis specific stress, Table 16 gives the numbers and percentages:

Table 16: Clinical cut off scores: numbers and percentages in treatment and control groups for anxiety, depression and psoriasis-specific stress

	Anxiety				Depression				Psoriasis-stress			
	Pre		Post		Pre		Post		Pre		Post	
	N	%	N	%	N	%	N	%	N	%	N	%
Treatment	8	50	7	43.8	6	37.5	5	31.3	13	81.3	11	68.8
Control	5	31.3	5	31.3	5	31.3	7	43.8	9	56.3	7	43.8

Therefore in the treatment group the number of people above clinical cut off decreased on all three measures over the treatment period. In the control group, the number of people above clinical cut off stayed constant on the measure of anxiety ,increased on the measure of depression, and decreased for psoriasis specific stress.

9.7 Individual comments by group participants

Other qualitative questions on the form asked “as a result of the group, do you intend to use any new or different coping strategies, if so, what ?” “what did you find most helpful?”, “what did you find least helpful ?”, and a space for any other comments.

Fig 5

New or different coping strategy

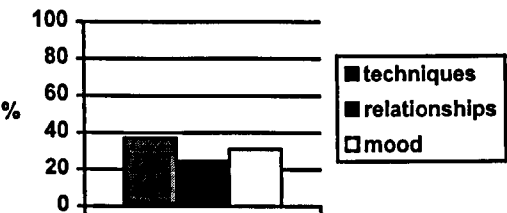


Fig 6

What did you find most helpful



% = percentage of participants making comments which related to that category. Figures do not add to 100% as some participants made more than one comment.

Figures 5 and 6 above give the percentage of comments grouped into three themes for each question. Answers to use of a new or different coping strategy were grouped into three categories. Specific coping techniques were mentioned by six people, such as “writing things down that concern me”, “dealing with each small thing at a time”, “challenging negative automatic thoughts”. The relationships category, referred to by four people, consisted of comments relating to assertiveness, confidence or being an equal: “try not to spend too much time worrying what others think”, “try to think of myself as an equal”. The third category, mood, was referred to by five people: “take a more positive approach”, “try not to enter vicious circles so much”. Six people left this question blank.

Answers to the question “what did you find most helpful” were grouped into the three categories of sharing concerns with others, learning coping strategies and increased understanding of thoughts and feelings. In the first category, mentioned by 14 people, were comments such as “realising that I am not the only one”. The second category, which five people referred to, consisted of comments such as “learning coping techniques”, “how to cope in different ways”, “evaluate the situation in order to prevent negative thoughts from overtaking”. In the third category, four people mentioned greater understanding of their own and others’ thoughts and feelings - “stopping to think about people’s reactions to psoriasis and my reactions to them”.

The question about what was least helpful was left blank by four people (25%), while four people stated that it had all been helpful (25%). Three people (18.8%) mentioned the group process, including the lack of commitment from group members who had discontinued, or the lack of understanding of certain group members (these three were all members of the same group). One person mentioned the travelling, one person the little headway with medical treatments, one the lack of a social collective approach to psoriasis and one person wished the meetings had been longer.

IV DISCUSSION

The discussion will begin with a section summarising the results, then consider methodological problems in sections 2 and 3. Section 4 will interpret the results in terms of the application of the coping framework to psoriasis and sections 5 and 6 will review clinical and research implications.

10.1 Summary of results

This two pronged investigation into chronic psoriasis and coping aimed to consider the role of coping strategies in mediating the influence of psoriasis on subjective disability and psychological distress, and to explore the efficacy of a group based intervention using a Coping Effectiveness Training format.

10.1.1 Overall sample characteristics

The overall initial response rate of 45% was similar to 49% reported in an investigation of psoriasis sufferers recruited from dermatology clinics (Finlay & Coles, 1995) which is lower than figures of 60% to 71% typically reported for community surveys from G.P. practices (Koo, 1996; O'Neill & Kelly, 1996). Gender distribution, duration of psoriasis and proportion of participants who were in paid employment were similar to previous investigations. The mean age of 49.7 years was slightly higher than means of 35 years (Ramsay & O'Reagan, 1988) to 46 years (Koo, 1996) reported in the literature, skewed by a high proportion of respondents in their late 60's. In terms of psychological distress, the figures demonstrated that this sample of people with psoriasis were exhibiting elevated depression and anxiety (27%) and worry due to psoriasis (62%), figures consistent with the research (McHenry & Doherty, 1992; McKenna & Stern, 1997).

10.1.2 Study one results

The first study investigated the coping strategies mediating the impact of psoriasis on subjective disability and psychological distress. Subjective disability was best accounted for by the measure of anticipatory-avoidance behaviour as found by Fortune et al (1997b), rather than by the variables of age, duration of psoriasis, gender, anxiety and depression. Beliefs in, or experience of, others' negative evaluations only added a small (3%) independent contribution to the variance predicted by behaviour; venting emotions was the variable best accounting for the remaining variance (7%). When the reciprocal relationship between the outcome variables themselves was removed, coping strategies of venting emotions, mental disengagement and alcohol use accounted for a significant proportion of the variance on measures of psychological distress and subjective disability with venting emotions accounting for between 24% and 48% of the variance and being the strongest coping predictor, appearing in all regression models. These coping strategies were found to be more important than age, gender and psoriasis duration in accounting for psychological outcome and, along with denial and behavioural disengagement, correlated positively with psychological distress, findings which are consistent with research into coping strategies in spinal cord injury (Kennedy et al in press). In addition, age was significantly negatively correlated with maladaptive coping strategies and psychological distress. There were no significant gender differences on measures of distress or subjective disability, but the coping strategy of venting emotions was positively associated with female gender. Adaptive coping strategies were generally high in the sample as a whole. Apart from a small contribution (in the positive direction) from positive reinterpretation in predicting anxiety, adaptive coping strategies did not appear in the regression models. In contrast

to previous findings in chronic health conditions, active coping was significantly positively related to subjective disability and to psoriasis specific stress.

10.1.3 Study two results

The second study, the pilot intervention, indicated that it was possible to engage psoriasis sufferers in a series of evening groups based on the format of Coping Effectiveness Training. Twenty nine people out of the overall sample of 89 agreed to attend the groups (33%) and of these, 16 people completed, a rate of 55%. These attendance rates were positive given the reported difficulties with engaging psoriasis sufferers in group based psychological interventions, with uptake in past studies found to be as low as 10% (Fortune et al, 1998). Structured coping groups have also been found to have higher drop-out rates than non directive, supportive groups, possibly due to the greater commitment required of participants (Schwartz, 1999). In terms of perceived usefulness, the group intervention yielded positive individual feedback which mentioned use of specific coping techniques learnt during the groups. Increase in perceived ability to cope as a result of the group correlated significantly with reductions in the measure of anxiety. However there were no significant group*time interaction effects on outcome variables or on use of adaptive coping strategies, although there was a trend for a decrease in subjective disability in the intervention relative to the control group.

10.2 Methodological Limitations: study one

10.2.1 Sample

The sample was recruited from two different sources simultaneously; the hospital dermatology clinic and the psoriasis self help group, introducing possible extraneous variables. Although initial scores on the questionnaire measures were not significantly different between these two sources there may have been other systematic differences between the sources such as differences in psoriasis severity, which were not measured by this study. According to previous research, the proportion of people with psoriasis in the community seeing a dermatologist was approximately 15% (Ramsay & O'Reagan, 1988), and the proportion of sufferers recruited through G.P. practices who are members of the psoriasis association was approximately 3% (O'Neill & Kelly, 1996). The study thus represented a subset (those who responded) of two subsets of psoriasis patients (the hospital outpatient clinic and the psoriasis association). Recruiting from the psoriasis association may have introduced systematic bias to the sample as those who had decided to join the association were arguably people who utilised social support and active coping to a greater extent than non-members. Overall, the relative dearth of respondents from the younger age bracket of sufferers could be due to bias in the sources from which sufferers were recruited, local geographical bias in age distribution of psoriasis, or may suggest that older people were more likely to respond to the study. It is a possibility that younger people were less likely to respond, and a speculation could be that perhaps self consciousness and feelings of stigmatisation were more salient in the younger age group, as found in the research (Gupta & Gupta, 1995b) which may have inhibited involvement in the study.

10.2.2 Measures

No measure was taken of psoriasis severity: previous research has shown poor correlations between objective and subjective measures of severity (Root & Kent, 1994) and this study aimed to look at the effect of the intervention on people's perceived disability in daily life due to the condition. The measures used may not have been representative of peoples' condition throughout the time period of data collection due to the fluctuating nature of psoriasis and changes in treatment.

10.2.3 Implementation and evaluation

The cross sectional design did not enable a causal link to be investigated between maladaptive coping strategies and the outcome measures. It would have been useful to conduct a follow up to ascertain the nature of these relationships and the extent of their stability over time.

10.3 Methodological limitations: study two

10.3.1 Sample

Participants were not excluded from the pilot intervention on the basis of comorbid medical or psychological difficulties with the exception of those receiving ongoing psychological treatment (one person). The sample participating in the intervention were self selected and allocation to treatment or control group was not randomised. While these factors were prohibitive in terms of investigating pure treatment effects (Chambless & Hollon, 1998), they did allow clinical effectiveness - the real life application of the intervention - to be ascertained. Clinical effectiveness may be poorly related to the results from pure research trials (Berger, 1996).

10.3.2 Measures

Although questionnaires were obtained within a month of commencing the intervention groups, there may still have been considerable change in scores on the measures used within this time. Psoriasis exhibited seasonal variation for many sufferers, and the groups were conducted from a time period spanning October to April. The sample sizes in the pilot intervention were too small to permit comparisons between the three intervention groups and it may have been that these three groups differed significantly from each other. The first intervention group was mainly composed of the hospital outpatients, while the second and third groups were mainly composed of members of the psoriasis association.

The measures used may not have detected change along all relevant dimensions. Self efficacy has been postulated as a mechanism through which change may occur following Coping Effectiveness Training (King & Kennedy, 1999) which was supported anecdotally by group participants who referred to increased self confidence following the groups. A measure of self efficacy may have yielded useful information. There was no measure of self concept which, with hindsight following group discussions, may also have been informative to ascertain. Difficulties with the COPE measurement will be discussed further in following sections.

10.3.3 Implementation and evaluation

In the pilot study the three intervention groups were each different in composition and character, which made them all interesting and informative to run but also introduced biases in that they could not be conducted identically, even though the same

framework was used. The groups were conducted by the researcher alone, with no external checks on constancy of group material and it was likely that the learning experience of conducting the groups led to their slight modification over time. This study differed from Coping Effectiveness groups conducted with inpatient samples who were in the same environment while the groups are in progress, and largely isolated from outside events. In the psoriasis groups, many of the individuals were also in the midst of various life events or daily stresses which at times, took precedence over psoriasis in the discussions, but always with a focus, such as coping with multiple demands, problem solving, vicious cycles. In some cases psoriasis onset was believed to have been precipitated by a major life event such as a bereavement. This demonstrated how psoriasis interacted with and amplified other life stresses and the impossibility of disconnecting psoriasis from these events.

A follow up may have yielded interesting results: it is increasingly recognised that psychological interventions may continue to have beneficial effects after their cessation, particularly if emphasising acquisition of new, stable skills (Chambless & Hollon, 1998).

10.4 Application of coping theory and intervention to psoriasis

The condition of psoriasis differs in many significant ways from other groups to which theories of appraisal and coping, and Coping Effectiveness Training, have been applied. It is not life threatening, the population is more heterogeneous than for spinal cord injury (predominantly young adults, more male than female), or the HIV studies which have been restricted to homosexual men. In addition, the condition itself varies widely not merely across individuals but fluctuates within individuals, from intense,

debilitating relapses to periods of remission. Psoriasis may also be distinguished by its degree of chronicity: it often appears at puberty or in early adulthood and so may become inextricably linked with development of social identity and self concept due to its visibility and associations with stigma.

The average duration of psoriasis in the sample was over 20 years so most individuals had very established ways of coping and were familiar with psoriasis and its difficulties. In contrast, Coping Effectiveness Training in spinal injury was introduced as part of the rehabilitation during the early weeks / months post injury, while Coping Effectiveness Training in HIV was linked to the post diagnosis phase - in itself marking a discrete event. Educative coping groups encouraging the contemplation of new, adaptive strategies and to reduce the fear of an overwhelming event would seem to be timely at this point. In the case of psoriasis, coping needed to be conceptualised in the context of established ways of living with the chronic condition.

Within the context of these differences, it was interesting to examine the findings.

10.4.1 Study one: Coping strategies

The findings of study one contributed to the increasing body of research on the role of adaptive and maladaptive coping in chronic health conditions and provided new information on the coping strategies influencing subjective disability and psychological distress in psoriasis. When considering the influence of coping and demographic variables on each outcome measure, the empirically defined maladaptive strategy of venting emotions accounted for the largest proportion of the variance, (between 24% to 48%) on measures of anxiety, depression, psoriasis specific stress and subjective

disability - appearing as a consistent factor in all regression models. While expressing emotions is believed to be healthy and is linked to acceptance of the losses inherent in a chronic condition, venting emotions refers to persistent emotional preoccupation with negative or unbearable aspects of a condition. Venting emotions may directly influence mood and may also occupy attentional resources, reducing capacity for other, more adaptive strategies. There are aspects of psoriasis which may predispose sufferers to experiencing intense emotions: as well as the lack of known cause, poor controllability and unpredictable course of the condition which may give a sense of battling with an invasive force (Jobling, 1992), there is social experience of rejection, perceived lack of public awareness or interest in the condition, lack of role models of individuals with psoriasis, and stigmatisation. These are ingredients which have been identified in the general literature and linked to feelings of humiliation, shame and guilt as well as anger towards treatment by others (Gilbert, 1997). A questionnaire assessment revealed that 46% of outpatients reported moderate or severe anger during psoriasis flares (Fried et al, 1995). Anger has also been conceptualised in chronic illness as part of a response to loss (Ogden 1996, Ch.13), and may also be present due to ongoing rejection and victimisation in the sufferer's life (Lewis, 1998). The strong association found in this study between venting emotions and subjective disability and distress thus has important implications for how the condition is viewed and dealt with by the individuals with psoriasis themselves, and the influence of their families and society.

While the maladaptive strategies previously identified in other medical conditions were also shown to be influential in psoriasis, the predicted relationship with adaptive strategies was not found in this study: there were no significant negative associations between adaptive coping strategies and psychological impact and one significant

positive association between active coping and subjective disability and psoriasis-specific stress. In general, the sample were exhibiting high levels of adaptive coping, consistent with research showing that people with psoriasis are well adjusted socially (Dooley & Finlay, 1989). The lack of association between adaptive coping and positive outcome may be due to difficulties in measurement of adaptive coping, which will be discussed further, but there may also be important differences in the coping of those who suffer from psoriasis as opposed to other conditions. Often psoriasis can be concealed, especially in the winter, and people may go to great lengths not to be identified as having the condition. So a constant striving not to draw attention to psoriasis and not to appear inadequate may utilise strategies defined as adaptive, such as active coping and planning, but which may nevertheless be a source of anxiety and distress, initiated in attempts to compensate for the condition. There is some evidence that in experimental studies people with psoriasis demonstrated good interpersonal adjustment yet reported high levels of anxiety (Weinstein, 1984). Interestingly, in contrast to the findings in other chronic health conditions, acceptance did not correlate with any measures of psychological outcome. Self reported acceptance has previously been documented in the literature as important in adjusting to life with psoriasis (Kang Seng, 1997) but acceptance in the context of psoriasis may take a different meaning. In conditions such as cancer and HIV there may be acceptance for the progressive and potentially terminal implications of the diagnosis. In the case of psoriasis, acceptance may rather be linked to acceptance of identifying oneself as someone with psoriasis and accepting oneself - a meaning which may not be picked up by the COPE measurement. A positive sense of self may be central to the ability to live with the condition and is linked to the concept of shame - a belief in aspects of oneself as inherently flawed and a subsequent devaluing of oneself and status relative to others (Gilbert, 1997). In this way

the role of psoriasis in individuals' experience of themselves, both in the present and in a developmental context, may have directly influenced psychological well-being.

10.4.2 Study One: Demographic factors in coping

The finding that age was significantly inversely correlated with all outcome variables except depression was consistent with the literature suggesting that psoriasis has greater psychological impact on younger people (Gupta & Gupta, 1995b). Duration of psoriasis was significantly inversely correlated with anxiety and subjective disability suggesting a lessening of psychological distress over the duration of the condition. Similarly duration of psoriasis, but not age itself, was significantly correlated with acceptance, suggesting a specific illness-adjustment process (although as noted above, acceptance itself was not correlated with psychological well-being). In terms of coping, this study found a significant inverse relationship between age and use of maladaptive strategies. It may have been that greater use of maladaptive strategies in younger people predicted greater levels of distress. As this was a cross sectional study direction of causality could not be predicted, but it is known that maladaptive strategies in themselves are likely to be associated with psychological distress. In terms of social and occupational functioning, the literature has suggested that psoriasis may have greater impact on young people who are establishing relationships, rather than in an existing, established network (Koo, 1996). Social avoidance and disengagement may then act to further isolate young individuals and increase their distress. Use of alcohol in order to cope was also significantly inversely associated with age and has been linked to rejection and stigmatisation (Ginsburg, 1995). However, use of humour and positive reinterpretation, adaptive strategies, were also inversely associated with age, which may suggest that younger people also employ a greater variety of coping strategies, or are more aware of

doing so. In the context of the importance of venting emotions as a predictor of psychological distress, it was interesting that females were more likely to utilise this coping strategy. However, the overall scores on outcome measures did not differ significantly between males and females. The greater use of venting emotions among the women in the sample may have been related to demographic factors such as occupational status. In a working environment there may be more distractions from the condition, venting emotions may be more inhibited and self esteem may be increased. It would have been interesting to determine if these gender differences still existed in a sample matched for occupation. The literature on gender differences in the impact of psoriasis is mixed (O'Neill & Kelly, 1996), suggesting the interaction of many factors are involved.

10.4.3 Study two: Coping Effectiveness Training for psoriasis

Study two was successful in engaging a community sample of psoriasis sufferers to participate in evening groups using the format of Coping Effectiveness Training: three evening groups were run, each of seven sessions. Between nine and ten people were invited to the groups which was the maximum for the room capacity and similar to the size of other groups run with psoriasis sufferers (Price et al, 1991). The 55% completing the groups is lower than that reported for other CET groups (Chesney & Folkman, 1996; King & Kennedy, 1999), but comparable to groups for a community sample of psoriasis sufferers who have been found to be difficult to recruit, considering that the group sessions spanned a seven week period and were utilising a structured problem focused format, which has been associated with better outcome but higher drop out rates than non directive support (Schwartz, 1999).

For some participants, attendance necessitated a considerable drive on dark evenings, and demonstrated that there was perceived need for, and willingness to attend, such groups. Feedback, and group discussions, made it clear that there was a sense of isolation among sufferers in the community in coping with the impact of the condition. Factors which enhanced the engagement seemed to be the interest and support of both the medical staff at the dermatology clinic and the psoriasis association. An emphasis on the practical, problem solving focus of the groups and on the difficulties of living with psoriasis seemed to evoke the interest and support of sufferers.

The other aims of the group were to ascertain whether a Coping Effectiveness Training group would reduce psychological distress and subjective disability, and enhance adaptive coping.

While there were no significant changes on any of the outcome measures relative to the control group, there was a trend for a relative decrease in subjective disability in the treatment group. Within-group analyses yielded a significant reduction in subjective disability in the treatment group post intervention. Significant findings from within group analyses in the absence of group*time interaction effects have been documented in stress management groups for people with atopic dermatitis (Neibel 1991, cited in Ehlers et al, 1995). Several reasons for lack of significant findings in this study could be postulated: that the groups were not useful in achieving their aims, that the changes were not being measured by the instruments used, that the changes were not measurable in such a small sample. Participants feedback was largely positive showing that the groups were perceived to be useful. In addition, individual feedback made specific reference to use of appraisal and coping techniques. The importance of enhanced

understanding of self perceptions and perceptions of others, through considering automatic thoughts and assumptions, was also highlighted. Comments such as “when ones emotions are running high and the negative thoughts kick in I found it most helpful to learn how to deal with this: to evaluate the situation in order to prevent the negative thoughts overtaking and evolving into a vicious cycle”; “I will deal with each small problem and not let them build up and get out of control”: demonstrated that not only were the groups serving a supportive function, but were enhancing people’s awareness of the role of the coping strategies they employed in moderating their thoughts and mood. The ratings of perceived increase in ability to cope as a result of the group intervention correlated significantly with decrease in anxiety over the intervention period, suggesting measurable change associated with perceived enhancement of coping ability. Individual change in scores (Appendix 9) showed that some participants did seem to benefit on the outcome measures. There were a few negative comments which related to difficulties due to group members who discontinued, highlighting the importance of a stable group environment, and the disruption of people not being able to attend on certain nights, or discontinuing; difficult to avoid for practical reasons with a community sample. Closer matching of participants may have reduced discontinuers: group two had the highest rate of discontinuers and this sample seemed to be the most disparate one in terms of views of psoriasis and concerns. There may be both advantages and disadvantages to such mixed groups: people may feel that the groups do not provide a setting where they can speak freely and be understood. Conversely, such settings may provide opportunities for mutual influence, and diversity of coping strategies may fuel change to a greater extent than a forum where concerns and ways of coping are very similar (Schwartz, 1999). Differences across the age range was a theme discussed at length in the third group, which spanned from 26 years to 65 years. Some

younger members became determined to be less concerned about the view of others and to resume discarded activities. One woman returned to a group meeting and announced that she had been swimming during the previous week, inspired by the discussion that had taken place. The group therefore showed the potential benefits of a range of ages and experiences.

In terms of the aim of enhancing adaptive coping, there were no significant increases in adaptive coping strategies, although interestingly, most participants commented not just on an increased ability to cope, but made reference to specific techniques discussed, such as “I shall try to be more assertive with the help of the ‘Six assertiveness skills sheet’”; “I shall concentrate on writing things down that concern me”. One possible explanation is that there was a ceiling effect - the initial scores on adaptive coping strategies as measured using the COPE were already high. The COPE may be a poor measure of change, and may be measuring dispositional, rather than situational coping, which would tend to retain stability over time (Kennedy et al in press). Another possibility raised earlier in the discussion is that those strategies empirically defined as adaptive were actually linked, in psoriasis, to people striving hard to compensate for perceived inadequacies and therefore were also linked to experience of stress and anxiety. Consistent with the literature on stigma in people who have psoriasis, group discussions provided some evidence of an intense feeling of self disgust in some individuals who were themselves repulsed by psoriasis and their own appearance. It emerged that people often pushed themselves to work hard and to be valued along other dimensions in order to counterbalance the feared negative impact of their appearance and own underlying sense of inadequacy. Shame was found to be a useful concept to discuss in the groups, and related to individual’s current experiences of rejection as well

as when young, for example being bullied at school as a result of psoriasis. Anger was also a central focus of people's experience of living with psoriasis, and was reported to interfere detrimentally with emotional well-being.

10.5 Clinical implications

Several implications can be drawn from the two studies constituting this investigation. The results have highlighted the elevated levels of psychological distress which exist in the population of people with psoriasis, and has provided some evidence that maladaptive coping strategies, particularly the venting of emotions, significantly predict subjective disability and psychological distress in this population.

These findings support the development of structured interventions to target coping strategies, with the aim of reducing subjective disability and ameliorating distress.

Judging from the sense of isolation expressed by sufferers, it would seem to be important to incorporate structured groups into a medical framework of care, offering a holistic approach to the condition and recognising its psychological impact. The education of medical professionals with regard to the psychological aspects of psoriasis and ways of coping with the condition would seem to be important. There may be a role for training other professionals or lay people in conducting structured self help coping groups, as has been successfully undertaken in the psychological management of rheumatoid arthritis (Lorig, Gonzalez, Laurent, Morgan, Laris, 1998).

The results of study two, the pilot intervention, indicated that the psoriasis population showed an interest in problem focused groups and that from subjective evaluation the Coping Effectiveness Framework was an appropriate one relevant to the needs of this population. While the standard measures did not yield significant differences relative to

the control group there were sufficient indications of beneficial effects from the group intervention to warrant further study.

Engagement in this study was believed to be enhanced by the support of the medical profession and the psoriasis association and demonstrated the importance of integrating the intervention with existing care so that the link between medical care and coping with the condition is endorsed as part of an approach to dealing with psoriasis which maximises quality of life. The nurses at the ward where the groups were run had expressed an interest in establishing groups in the future and there are plans for the group format to be discussed with the medical team.

It was interesting to observe that, out of the three intervention groups conducted, individuals in the first group composed mainly of a subset of sufferers recruited through the hospital dermatology clinic seemed to benefit to a greater extent on outcome measures than those recruited through the psoriasis association. The pattern of change can be observed from the individual score changes for each participant (Appendix 9). While the sample was too small to permit between-group analysis of the three intervention groups, it may have been that there were certain subgroups of sufferers more likely to benefit from a structured coping focused intervention, as has been suggested in Multiple Sclerosis (Schwartz, 1999). Targeted interventions, if subgroups were identified accurately, would be likely to be cost effective. From the current study it can only be speculated why there may have been a differential response to the intervention between hospital clinic and self help subgroups. Possibilities include that the hospital recruits were suffering from more severe psoriasis or were receiving less pre-existing social support, or exhibited more commitment to the intervention. If it

could be established that certain groups were most at risk, or most likely to benefit from Coping Effectiveness Training, interventions could be moulded to the needs of these groups. One subgroup suggested by the current study as potentially benefiting from a structured coping group was the younger age group of sufferers. Comments from participants who attended the groups suggested that they would have particularly valued a version of Coping Effective Training when they were young: “It would have been most helpful for me to be involved in a coping group in my early 20’s”; “ I just wish something like this could have been formed some time ago ... it was so nice to think that at last it is being looked at by people without the problem”.

The adaptation and modification of the Coping Effectiveness Training format would follow from increased research and knowledge of coping with psoriasis.

10.6 Research implications

The information in study one highlighted the need for more research into the utilisation of coping strategies in this population, in particular to further investigate the role of adaptive coping strategies in psoriasis, and to develop measurements of coping that are sensitive to change. It would be interesting to conduct longitudinal research to identify whether maladaptive coping strategies have a predictive role in psychological distress, and the extent to which such coping is stable or fluctuates with change in the condition. The chronic nature of psoriasis provides a different context in which to investigate coping - in particular, whether a distinction can be made between dispositional and situational coping. The COPE only measures the presence or absence of certain strategies, may not be sensitive to change, and does not inform us as to the salience of the strategies. For example, people may indicate that they plan, but the quality or effectiveness of the planning is not known. There is a need for more direct measures of

coping, such as through use of diaries and semi-structured interviews (Coyne & Gotlieb, 1996).

This discussion has suggested that stable negative self concept may predispose to shame, and hence psychological distress, even in the presence of adaptive coping. The emotional state of shame occurs when internal global negative attributions are made from events, leading to characterological rather than behavioural self-blame (Lewis 1998). Shame prone individuals may cope adaptively with psoriasis, but attribute failings or difficulties to flaws in themselves, whereas those experiencing rejection but with relatively high self concept may attribute rejection specifically to psoriasis, with less detrimental effect on overall self perception. Longitudinal research in psoriasis has provided some evidence for the existence of stable negative self concept in patients regardless of the current state of their skin (McKenna & Stern, 1997). Schwartz (1999) conducted directive problem focused groups with people who had multiple sclerosis and found that self blame and blaming of others both decreased in the intervention group - evidence that these can be addressed in a time limited, structured intervention. Recent research has demonstrated the direct influence of illness beliefs on subjective disability which were not mediated by coping response (Scharloo et al, 1998). Illness beliefs include beliefs in perceived cause, consequences, controllability, duration and identity and therefore denote the meaning of the illness to the individual.

Therefore not only do sensitive measures of coping strategies need to be developed but further understanding of the complex interaction between illness beliefs, shame, coping strategies, subjective disability and psychological distress, would seem to be a useful focus for future research.

V: CONCLUSIONS

The main findings from these two studies were:

- 1) Detailed analysis of the coping strategies used by psoriasis sufferers revealed that venting emotions and disengagement emerged as consistent predictors of subjective disability and psychological distress, being more important than age, gender and duration of psoriasis.
- 2) A community sample of sufferers were engaged to attend an intervention based on Coping Effectiveness Training and perceived this to be useful. Although there were no significant changes in the treatment relative to control group on outcome measures or adaptive coping, there was a trend towards relative reduction in subjective disability in the treatment group. Perceived increase in ability to cope due to the group was also found to correlate significantly with measured decrease in anxiety.

The pilot study demonstrated that evening groups in the format of Coping Effectiveness Training could be implemented for psoriasis sufferers in the community: the focus of the groups was valued by participants and perceived to lead to acquisition of coping skills.

It was suggested that there were enough interesting trends in the data and enough interest from participants to warrant further study and systematic evaluation of the use of CET in this population. It was suggested that developments and modifications in the CET format should ensue from further research into the detailed use of coping strategies in the population of people with psoriasis. A further suggestion was made that particular

subgroups may benefit differentially from the groups, such as those requiring outpatient treatment, and younger people, with particular attention required to engagement factors.

It was hoped that in the future some form of coping programme, which has the advantage of being structured and focused, may be integrated into the medical care regime and accessible to more people with psoriasis, particularly at the time of identification of the condition.

Implications for further research were highlighted as the need for further investigation into the processes involved in use of coping strategies, and their stability over time, in this population. In particular, the need to investigate the dynamic relationship between coping strategies, illness beliefs and identity, self concept and shame was emphasised, which will require improvements in direct measures of problem solving, and measures sensitive to change.

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APPENDICES

- 1 Ethical approval and confirmation of indemnity
- 2 Letter introducing the study
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 - Psoriasis Life Stress Inventory
 - COPE scale
 - Hospital Anxiety and Depression Scale
- 6 Letter to control group
- 7 Participants feedback sheet
- 8 Summary of intervention content
- 9 Individual change in scores on outcome measures

APPENDIX 1

Ethical approval and confirmation of indemnity

Manor House
Headley Way, Headington
Oxford OX3 9DZ

Tel: 01865 222692/222547
Fax: 01865 222699

Our Ref. DG/eb/O98.23

2 July, 1998

Dr Paul Kennedy
Consultant Clinical Psychologist
Warneford Hospital
Oxford

Dear Dr Kennedy

Re: OFREC O98.23 -Using Coping Effectiveness Training to Help People Cope with Psoriasis

Thank you for your letter of the 25th June 1998 which satisfactorily answers the points raised in my previous letter of the 17th June 1998. This study now has full ethical approval subject to confirmation of indemnity.

Yours sincerely

David Geaney

Dr David Geaney
Chairperson
Oxfordshire Psychiatric Research Ethics Committee

Chairperson: Dr D. Geaney



The Warneford Hospital
Warneford Lane
Headington
Oxford
OX3 7JX

4 December 1998

Dr Paul Kennedy
Clinical Psychologist
Isis Education Centre
Warneford Hospital

Dear Dr Kennedy

I am writing to confirm that Oxfordshire Mental Healthcare NHS Trust will indemnify you and Ms Laura Hill for your research project, 098/23, 'Using coping effectiveness training to help people cope with psoriasis' as described in your application to the Psychiatric Research Ethics Committee. This commitment is dependent on the formal approval of the Oxfordshire Psychiatric Research Ethics Committee and on the understanding that you have contract of employment with this Trust.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Pam Groves".

Mrs Pam Groves
Acting Chief Executive

APPENDIX 2

Letter introducing the study

{Name}
{Address}
{Address}
{Address}
{address}

Dear -----,

I am a trainee clinical psychologist working with Dr. Susan Burge, Consultant Dermatologist, and Dr. Paul Kennedy, Consultant Clinical Psychologist. We are planning to carry out a study to increase our understanding of how to help people cope with living with psoriasis.

Research has shown that people with psoriasis experience a variety of feelings and concerns. Whatever your experience of psoriasis, we are interested in finding out how psoriasis affects your daily life and whether a new technique, called Coping Effectiveness Training, helps people with psoriasis to cope more effectively with their condition.

We would be grateful if you were willing to assist us with this research.

Please would you complete the enclosed slip, and return it in the prepaid envelope, to indicate whether or not you would be interested in finding out more about the research and in discussing the possibility of taking part. Your decision will in no way affect any present or future medical care for your condition.

Yours sincerely

Laura Hill
Trainee Clinical Psychologist.

Tel: 01865 226431

APPENDIX 3

Letter to participants, information sheet and consent form

(Tel: Isis Education Centre 01865 226431)

{Name}
{Address 1}
{Address 2}
{Address 3}
{Address 4}

23/11/98

Dear -----,

Study into Psoriasis and Coping

Thank you for expressing your interest in the above study.

Further to our telephone conversation in October, I am enclosing an information sheet about the study, the questionnaires, and a consent form.

I would be grateful if you could complete the questionnaires and consent form, and return them to me in the prepaid envelope. As you will see, there are four questionnaires. It should take about 15 minutes to complete all four. I would like to emphasise that all responses will be treated as strictly confidential and that the results will only be used for statistical analysis.

If you expressed interest in the group programme, I will contact you shortly after I receive the questionnaires.

If you were not interested in the group programme, or if you will no longer be able to attend a group, it would still be very helpful to receive your questionnaire responses, as this will increase our understanding of the experience of living with psoriasis.

Best wishes,

Yours sincerely,

Laura Hill
Trainee Clinical Psychologist

INFORMATION SHEET

DERMATOLOGY DEPARTMENT

Old Road
Headington
Oxford
OX3 7LJ

Research in several physical conditions and illnesses have demonstrated that building on existing ways of coping can help people to live with, and adjust to, some of the difficulties which arise from their condition. This technique, called Coping Effectiveness Training, has not yet been developed for people with psoriasis but, alongside existing treatments, may help to reduce the distress which psoriasis can cause. This study plans to increase our understanding of how to develop ways of coping for people who have psoriasis.

Enquiries: 01865-228232
Appointments: 01865-228206
Clinical FAX: 01865-228240
Ward 01865-228250

I would be grateful if you would consider taking part in this study. If you agree to take part, it would involve initially completing some questionnaires and rating scales to give us more information about the ways in which psoriasis is affecting your life, and how you deal with these difficulties.

Consultants:
Dr. R. P. R. Dawber
01865-228265

Dr. F. Wojnarowska
01865-228266

Dr. S. M. Powell
01865-228205

Dr. N. P. J. Walker
01865-228224/37

Dr. S. Burge
01865 228258

Senior Nurse
Miss J. Merryweather
01865-228250

Clinical
Measurement
Dr. G. W. Cherry
01865-228269/38

Laser Service
Mrs Cheryl Day
01865 228223

Medical Records
01865-228204

Business
Directorate:

SDU Director
Dr. S. M. Powell

Research
Director
Dr. G. W. Cherry

SDU Manager

General
Manager
Mrs. Jane Imbush
01865-225243

Admin FAX
01865-228260

If you are interested in attending the group programme, I will ask you to come to a group which would meet one evening weekly, for about an hour, for seven weeks. The meetings would take place at the Churchill Hospital and would be led by myself, and attended by other people with psoriasis who have agreed to take part in this study (a maximum of 9). The content of each meeting would be given at the start, and the focus would be on ways of coping. It is hoped that the groups would be interesting and enjoyable as well as useful.

Participation in the study is entirely voluntary and you may decide to withdraw from the study at any point. Your decision whether or not to take part will not influence any treatment that you are receiving, or may in the future receive. Any information obtained during the study will be treated as strictly confidential and questionnaire results will only be used for the purpose of statistical analysis.

Thank you for taking the time to consider participating in this study.

Laura Hill
Trainee Clinical Psychologist.

Dr. Paul Kennedy
Consultant Clinical Psychologist

Dr. Susan Burge
Consultant Dermatologist

Isis Education Centre

Tel: 01865 226431

DERMATOLOGY DEPARTMENT
Old Road
Headington
Oxford
OX3 7LJ

ROYAL COLLEGE OF PHYSICIANS CONSENT TO RESEARCH FORM

Title of project: Using Coping Effectiveness Training to help people cope with psoriasis.

Enquiries: 01865-22823
Appointments: 01865-22820
Clinical FAX: 01865-22824
Ward 01865-22825

Principal Investigators: Dr. Paul Kennedy
Dr. Susan Burge

Psychiatric Research Ethics Committee Application Number: OPREC 9823

Have you read the patient information sheet? Yes /no
(please circle your answer)

Have you had the opportunity to ask questions and discuss this study? Yes /no

Have you received satisfactory answers to all your questions? Yes /no

Have you received enough information about the study? Yes /no

Who has explained the study to you?

Dr/Mr/Mrs/Miss

Do you understand that you are free to leave the study
- at any time
- without having to give a reason for leaving
- and without affecting your future medical care?

Yes /no

Do you agree to take part in this study? Yes /no

Signature:

Date:

Name in block letters:

Consultant
Dr. R. P. R. Dawb
01865-22821

Dr. F. Wojnarowski
01865-22821

Dr. S. M. Pow
01865-22821

Dr. N. P. J. Walk
01865-228224/

Dr. S. Bur
01865 2282

Senior Nur
Miss J. Merryweath
01865-2282

Clini
Measureme
Dr. G. W. Che
01865-228269/

Laser Serv
Mrs Cheryl C
01865 2282

Medical Reco
01865-2282

Busin
Director.

SDU Direc
Dr. S. M. Pov

Resea
Direc
Dr. G. W. Che

SDU Mana
Mrs. Cheryl I

Clinical Cer
Mane
Mrs. Linda Ken
01865-225

Admin F
01865-228

APPENDIX 4

Demographic question sheet

Please would you answer the following questions.

Age:

Sex: male / female (please circle)

Marital Status: single married divorced widowed
(please circle)

Occupation:

Psoriasis duration:

Age at onset of psoriasis:

Medical treatment currently receiving for psoriasis:

APPENDIX 5

Standard measures

**Psoriasis Disability Index
Psoriasis Life Stress Inventory
COPE scale
Hospital Anxiety and Depression Scale**

PSORIASIS DISABILITY INDEX

Thank you for your help in completing this questionnaire. Please could you note the following points.

- 1. Every question relates to the LAST FOUR WEEKS ONLY.**
- 2. Every question should be answered by ringing one of the numbers from 0 - 6. "0" represents "Not at all" and "6" represents "Very much". The other numbers represent grades between these two extremes.**
- 3. There are two different versions of question 6, 7 and 8. If you are **at regular work or at school** please answer the first batch of questions **6 - 8**. If you are **not at work or school** please answer the alternative questions on page 2.**
- 4. Please note that there are 15 questions. Please check that you have answered all the questions on the three pages.**

PSORIASIS DISABILITY INDEX

All questions relate to the LAST FOUR WEEKS.

DAILY ACTIVITIES:

1. How much has your psoriasis interfered with you carrying out work around the house or garden?

Not at all = 0 1 2 3 4 5 6 = Very much

2. How often have you worn different types or colours of clothes because of your psoriasis?

Not at all = 0 1 2 3 4 5 6 = Very much

3. How much more have you had to change or wash your clothes?

Not at all = 0 1 2 3 4 5 6 = Very much

4. How much of a problem has your psoriasis been at the hairdressers?

Not at all = 0 1 2 3 4 5 6 = Very much

5. How much has your psoriasis resulted in you having to take more baths than usual?

Not at all = 0 1 2 3 4 5 6 = Very much

Continued next page

All questions relate to the LAST FOUR WEEKS.

WORK OR SCHOOL (if appropriate)

6. How much has your psoriasis made you lose time off work or school over the last four weeks?

Not at all = 0 1 2 3 4 5 6 = Very much

7. How much has your psoriasis prevented you from doing things at work or school over the last four weeks?

Not at all = 0 1 2 3 4 5 6 = Very much

8. Has your career been affected by your psoriasis? e.g. promotion refused, lost a job, asked to change a job.

Not at all = 0 1 2 3 4 5 6 = Very much

IF NOT AT WORK OR SCHOOL: ALTERNATIVE QUESTIONS

6. How much has your psoriasis **stopped you** carrying out your normal daily activities over the last four weeks?

Not at all = 0 1 2 3 4 5 6 = Very much

7. How much has your psoriasis **altered the way** in which you carry out your normal daily activities over the last four weeks?

Not at all = 0 1 2 3 4 5 6 = Very much

8. Has your career been affected by your psoriasis? e.g. promotion refused, lost a job, asked to change a job.

Not at all = 0 1 2 3 4 5 6 = Very much

Continued next page

All questions relate to the LAST FOUR WEEKS.

PERSONAL RELATIONSHIPS:

9. Has your psoriasis resulted in sexual difficulties over the last four weeks?

Not at all = 0 1 2 3 4 5 6 = Very much

10. Has your psoriasis created problems with your partner or any of your close friends or relatives?

Not at all = 0 1 2 3 4 5 6 = Very much

LEISURE:

11. How much has your psoriasis stopped you going out socially or to any special functions?

Not at all = 0 1 2 3 4 5 6 = Very much

12. Is your psoriasis making it difficult for you to do any sport?

Not at all = 0 1 2 3 4 5 6 = Very much

13. Have you been unable to use, criticised or stopped from using communal bathing or changing facilities?

Not at all = 0 1 2 3 4 5 6 = Very much

14. Has your psoriasis resulted in you smoking or drinking alcohol more than you would do normally?

Not at all = 0 1 2 3 4 5 6 = Very much

TREATMENT:

15. To what extent has your psoriasis or treatment made your home messy or untidy?

Not at all = 0 1 2 3 4 5 6 = Very much

Thank you for your help.

PLEASE TICK THE BOX THAT BEST INDICATES HOW PSORIASIS AFFECTS YOU

Please respond to ALL statements

	Not at all	Slight degree	Moderate degree	A great deal
1. Inconvenienced by the shedding of your skin				
2. Feeling self-conscious among strangers				
3. Feeling that you have to set aside a large part of your time to take care of your psoriasis				
4. Not going to public places (e.g., swimming baths, health club, restaurant) when you would have liked to				
5. Wearing unattractive or uncomfortable clothes in order to cover certain regions of your body				
6. Having to avoid sunbathing in the company of others				
7. Fear of having serious side-effects from medical treatment				
8. People treating you as if your skin condition is contagious				
9. Avoiding social situations				
10. Strangers (children or adults) making rude or insensitive remarks about your appearance				
11. Not enough money to pay medical bills				
12. Feeling like an "outcast" or "social misfit" a great deal of the time				
13. People making a conscious effort not to touch you				
14. Hairdresser appearing reluctant to cut your hair				
15. People implying that your skin condition may be due to AIDS, Leprosy, or a Venereal disease				

Response choices:

1. = I USUALLY DON'T DO THIS AT ALL
2. = I USUALLY DO THIS A LITTLE BIT
3. = I USUALLY DO THIS A MEDIUM AMOUNT
4. = I USUALLY DO THIS A LOT

		1	2	3	4
1.	I try to grow as a person as a result of the experience.				
2.	I turn to work or other substitute activities to take my mind off things.				
3.	I get upset and let my emotions out.				
4.	I try to get advice from someone about what to do.				
5.	I concentrate my efforts on doing something about it.				
6.	I say to myself "this isn't real".				
7.	I put my trust in God.				
8.	I laugh about the situation.				
9.	I admit to myself that I can't deal with it, and give up trying.				
10.	I restrain myself from doing anything too quickly.				
11.	I discuss my feelings with someone.				
12.	I use alcohol or drugs to make myself feel better (or would like to).				
13.	I get used to the idea that it happened.				
14.	I talk to someone to find out more about the situation.				
15.	I keep myself from getting distracted by other thoughts or activities.				
16.	I daydream about things other than this.				
17.	I get upset, and am really aware of it.				
18.	I seek God's help.				

		1	2	3	4
19.	I make a plan of action.				
20.	I make jokes about it.				
21.	I accept that this has happened and that it can't be changed.				
22.	I hold off doing anything about it until the situation permits.				
23.	I try to get emotional support from friends or relatives.				
24.	I just give up trying to reach my goal.				
25.	I take additional action to try to get rid of the problem.				
26.	I try to lose myself for a while by drinking alcohol or taking drugs (or would like to).				
27.	I refuse to believe that it has happened.				
28.	I let my feelings out.				
29.	I try to see it in a different light, to make it seem more positive.				
30.	I talk to someone who could do something concrete about the problem.				
31.	I sleep more than usual.				
32.	I try to come up with a strategy about what to do.				
33.	I focus on dealing with this problem, and if necessary let other things slide a little.				
34.	I get sympathy and understanding from someone.				
35.	I drink alcohol or take drugs in order to think about it less (or would like to).				
36.	I kid around about it.				
37.	I give up the attempt to get what I want.				
38.	I look for something good in what is happening.				
39.	I think about how I might best handle the problem.				
40.	I pretend that it hasn't really happened.				
41.	I make sure not to make matters worse by acting too soon.				

		1	2	3	4
42.	I try hard to prevent other things from interfering with my efforts at dealing with this.				
43.	I watch TV to think about it less.				
44.	I accept the reality of the fact that it happened.				
45.	I ask people who have had similar experiences what they did.				
46.	I feel a lot of emotional distress and I find myself expressing those feelings a lot.				
47.	I take direct action to get around the problem.				
48.	I try to find comfort in my religion.				
49.	I force myself to wait for the right time to do something.				
50.	I make fun of the situation.				
51.	I reduce the amount of effort I'm putting into solving the problem.				
52.	I talk to someone about how I feel.				
53.	I use alcohol or drugs to help me get through it (or would like to).				
54.	I learn to live with it.				
55.	I put aside other activities in order to concentrate on this.				
56.	I think hard about what steps to take.				
57.	I act as though it hasn't even happened.				
58.	I do what has to be done, one step at a time.				
59.	I learn something from the experience.				
60.	I pray more than usual.				

Please indicate how you are feeling now, or how you have been feeling in the last day or two, by ticking the column to the right of each of the following statements:

	Yes definitely	Yes sometimes	No, not much	No, not at all
1 I wake early and then sleep badly for the rest of the night.				
2 I get very frightened or have panic feelings for apparently no reason at all.				
3 I feel miserable and sad.				
4 I feel anxious when I go out of the house on my own.				
5 I have lost interest in things.				
6 I get palpitations, or a sensation of 'butterflies' in my stomach or chest.				
7 I have a good appetite.				
8 I feel scared or frightened.				
9 I feel life is not worth living.				
10 I still enjoy the things I used to.				
11 I am restless and can't keep still.				
12 I am more irritable than usual.				
13 I feel as if I have slowed down.				
14 Worrying thoughts constantly go through my mind.				

APPENDIX 6

Letter to control group

{Name}
{Address 1}
{Address 2}
{Address 3}
{Address 4}

Dear .-----

Psoriasis and coping

You may remember that you filled in some questionnaires a few months ago, asking about the day to day difficulties that living with psoriasis may cause, and how you deal with them. At the time I asked if you would be willing to complete the same questionnaires later on, to help us understand how things naturally change over time.

I hope that you are still willing to do this.

I enclose a further set of the questionnaires and would be very grateful if you could take the time to complete them and return them in the prepaid envelope. These are the same questionnaires which you completed previously. It does not matter if your responses this time are not the same as before - it is important to answer according to how things are for you now, or during the last four weeks.

As you stated that you were unable to attend a group programme, I will not be asking you to participate further in the study. However, if you would like to receive a brief summary of the findings once the study is completed, please write a note on the questionnaires when you return them, and I will send this to you. The study should be finished by summer 1999.

Thank you for your help with this study.

Best wishes,

Yours sincerely,

Laura Hill
Trainee Clinical Psychologist

APPENDIX 7

Participants feedback sheet

Psoriasis and coping group

It would be very helpful to have your views on how useful you have found the group. Please would you answer the questions below, by circling the number on the rating scale, and add any other comments that you wish overleaf.

1) How useful did you find the group ?

0	1	2	3	4	5
not useful					very useful

2) What did you find the most helpful ?

3) What did you find the least helpful ?

4) Did you feel your concerns were addressed ?

0 1 2 3 4 5
not at all very much so

5) Did you feel able to express your concerns in this context ?

0 1 2 3 4 5
not at all very much so

6) As a result of the group, do you feel more able to cope with your concerns ?

0	1	2	3	4	5
not at all					much more able

7) As a result of the group, do you intend to use any new or different coping strategies? If so, what ?

Please add any other comments overleaf.

APPENDIX 8

Summary of intervention content

SUMMARY OF INTERVENTION CONTENT

Session one covers the aims of the group, introductions, and guidelines. Stress, and people's understanding of it, is raised. The relationship between stress and psoriasis is then discussed in pairs and ways in which psoriasis adds to stress in life, both due to particular events and external situations, and due to internal thoughts and worries. Lists of the external sources of stress in psoriasis and internal fears and concerns which contribute to stress are generated. Examples are given of the ways in which situations can be viewed as stressful due to both external factors and internal factors. This leads to a discussion of stress, appraisal and coping. People are asked to consider their own personal signs and reactions to stress during the week, and how these affect their lives.

Session two: people's individual reactions to stress are discussed and the theory of stress, appraisal and coping is reviewed. The process of appraisal of situations is outlined: defining the problem, breaking the problem down into small parts through use of who, what, where and when questions. This is practised as a group exercise through examples volunteered by individuals. The consideration of changeable versus unchangeable aspects to stressful situations, and to psoriasis, is emphasised. Adaptive coping - a good match between situation and coping strategy - is defined. People's changing reactions to psoriasis over time are examined to consider the role of coping, and the link of appraisal and coping. Acceptance for unchangeable aspects - the incurable nature of psoriasis - is discussed, as well as dealing with the intermittent nature of psoriasis. Attention is drawn to the role of avoidance as a way of coping with feared situations. People are asked to assess the changeability of stressful situations that evolve during the week, or a past situation which they would have liked to have handled differently, and to consider anything that is now avoided due to fear.

Session three outlines a six step model of problem solving. Problem scenarios are then passed around group members as an exercise with the group, using the application of the problem solving approach. Some typical scenarios used are:

- A relative keeps questioning you about your treatment, telling you of new remedies that you should try.
- You go to the swimming pool. After getting changed and walking into the pool area, you are asked to leave by a pool attendant.
- When your psoriasis is at its worst, your partner seems afraid to touch you.
- You are in a cafe with a relative and are hot. You take your jacket off. Your relative gets embarrassed and asks you to put it back on.
- You are at a job interview and become aware of scales falling off your skin.

Session four considers emotional reactions to having psoriasis, and outlines the link between thoughts, feelings and behaviour. The vicious cycle of panic is used as an example, and fuels an exercise on social anxiety, thoughts, feelings and physical changes in anxiety inducing situations. The impact of avoidance on thoughts, feelings and behaviour is discussed in the group, and the role of psoriasis in anxiety and avoidance. Self esteem and its link with low mood and withdrawal is outlined. A list of activities which help elevate self esteem and enable people to relax is generated by participants, and this is contrasted with unhelpful reactions and activities, such as turning to alcohol. Relaxation tapes are issued to participants.

Session five: the negative assumptions which underpin typical negative automatic thoughts are focused on with an emphasis on how automatic thoughts may be deceptive and may lead to a sense of disempowerment in situations. Typical assumptions behind some thoughts identified in psoriasis are generated such as “if people knew the real me they would reject me”. Shame is discussed and the role of early experiences of rejection. An example of identifying negative automatic thoughts and challenging them is given by the scenario of an acquaintance walking past without saying hello or smiling, and discussion generated about possible negative automatic thoughts. People then discuss in pairs situations and try to identify the automatic thoughts, and are asked to try to “catch” negative automatic thoughts during the week.

Session six: reviews the group content so far and allows time for discussion of the material raised. Differences between group members in their dealing with psoriasis, such as the role of age and gender in influencing the way in which situations are interpreted, and the coping strategies employed, are used to explore the ideas covered. and the importance of flexible, adaptive coping. Within individuals, changes in appraisal of psoriasis over time, and the interaction of other events in life, are considered. Life goals are discussed, and the importance of matching goals to realistic appraisal of what is attainable. The role of psoriasis in shaping life goals, and any positive value that can be gleaned from the experience of living with psoriasis, are reviewed.

Session seven is devoted to social support and social interactions. The importance of social support, and valuable sources of it, is discussed in the group. The difficulties posed by psoriasis are used to highlight assertive, passive and aggressive styles of interaction. People discuss a social situation they have been in lately that they found difficult, and how they would have liked to deal with it differently, and then one which they felt they handled well. The group ends by discussing any points that people feel has not been covered by other sessions, and what people would have liked to see included in a future group.

APPENDIX 9

Individual change in scores on outcome measures

BEST COPY

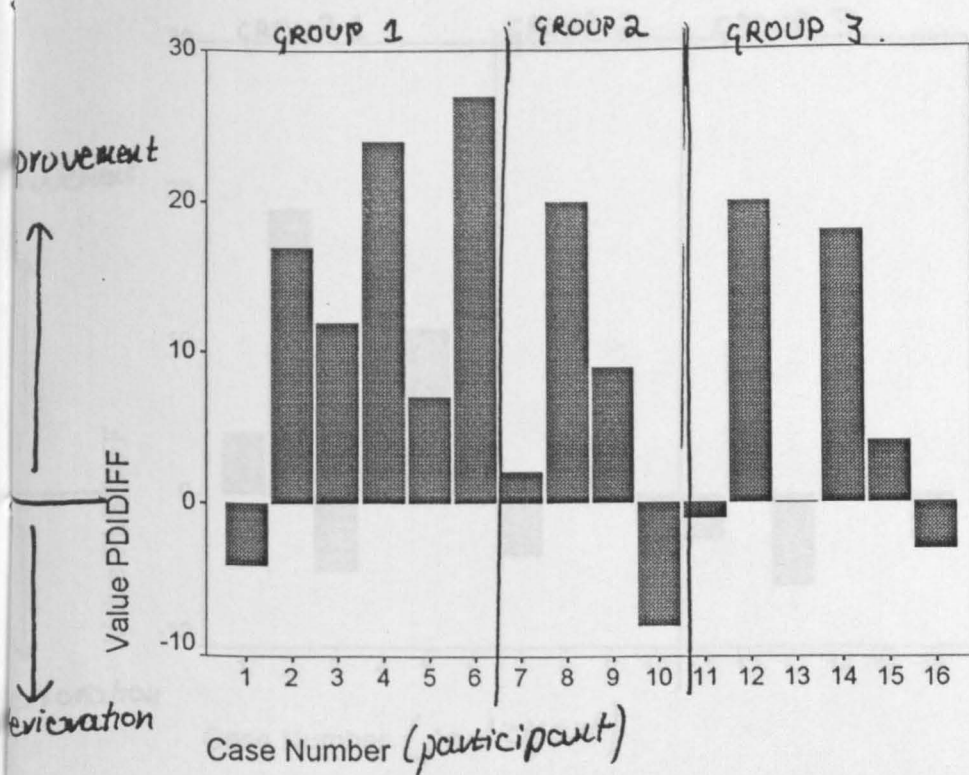
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Poor text in the original
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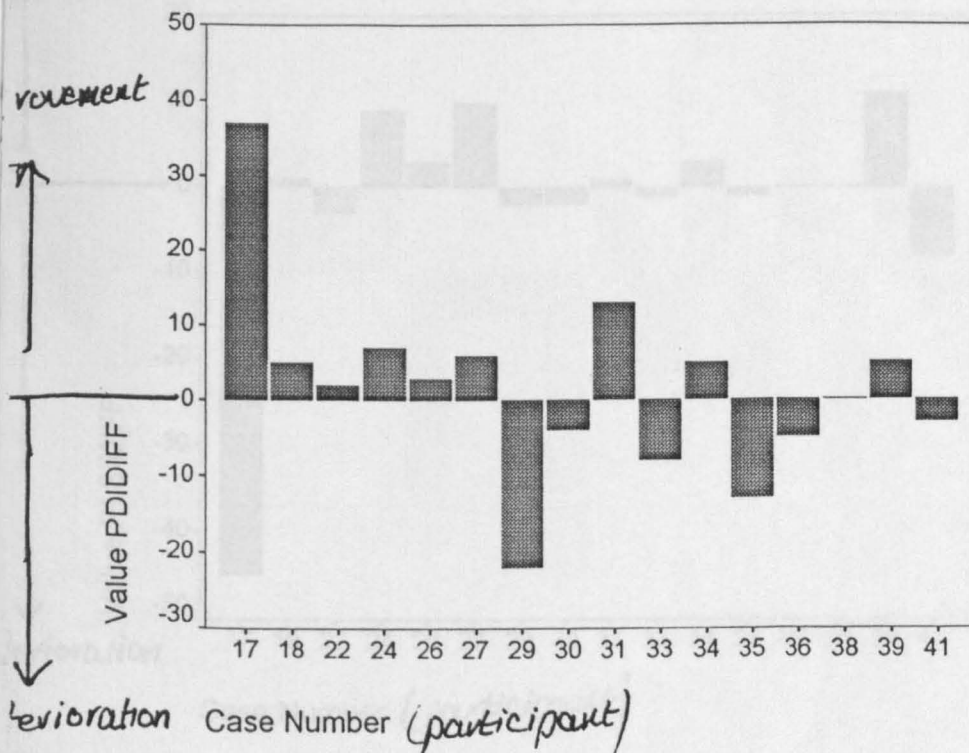
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the spine.

Some images distorted

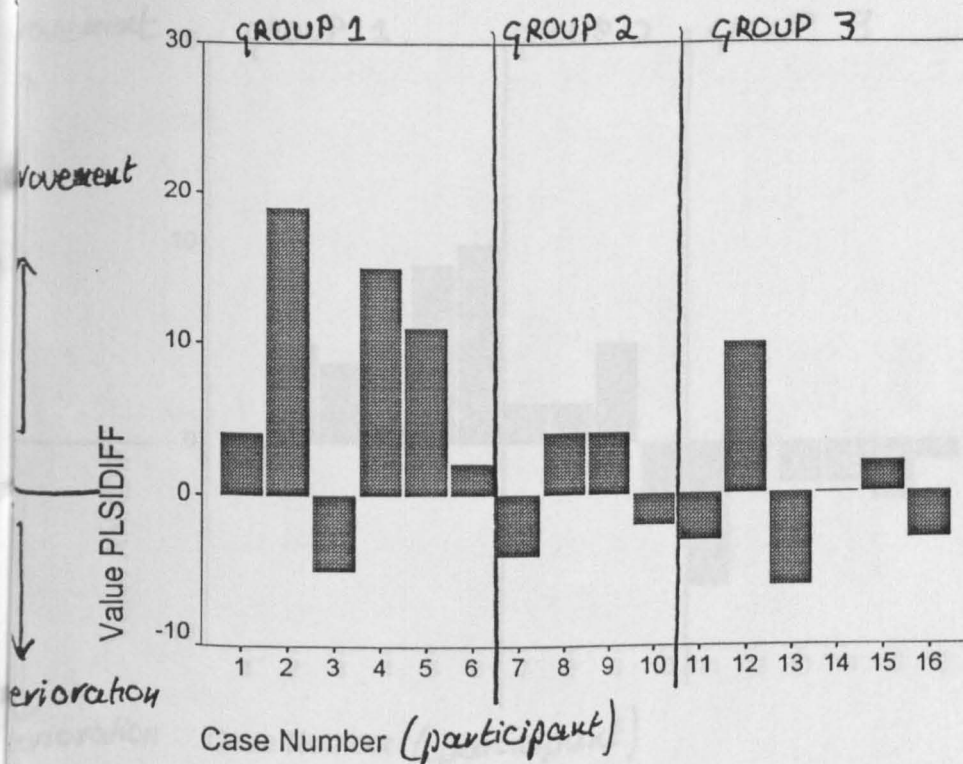
Treatment group individual change in scores: subjective disability



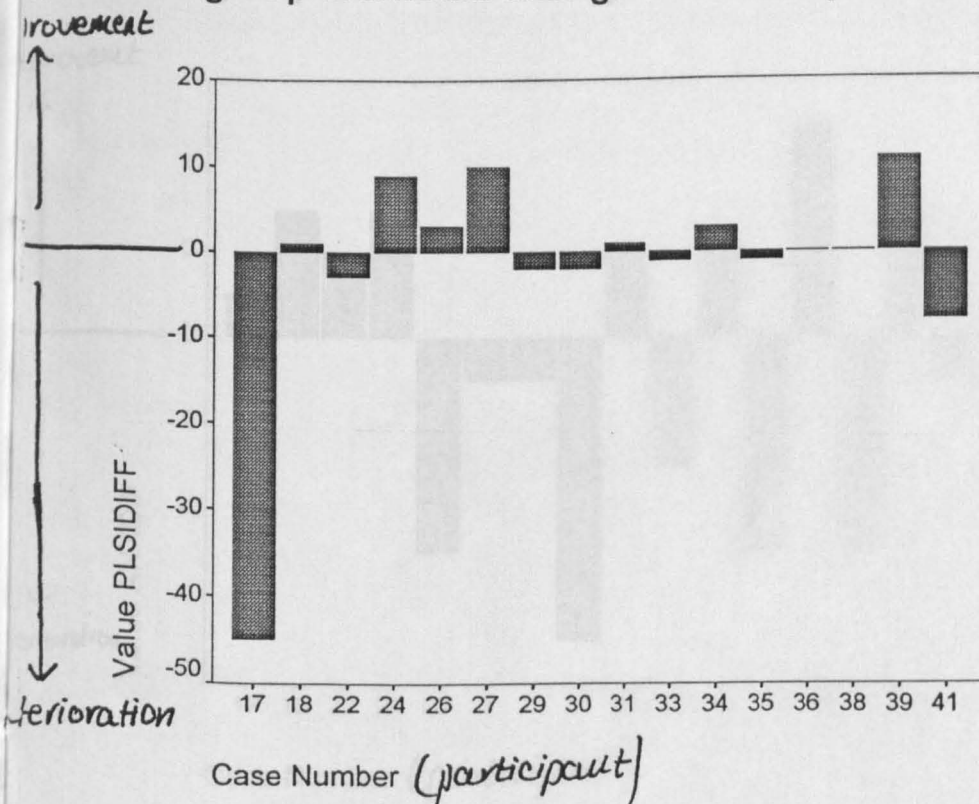
Control group individual change in scores: subjective disability



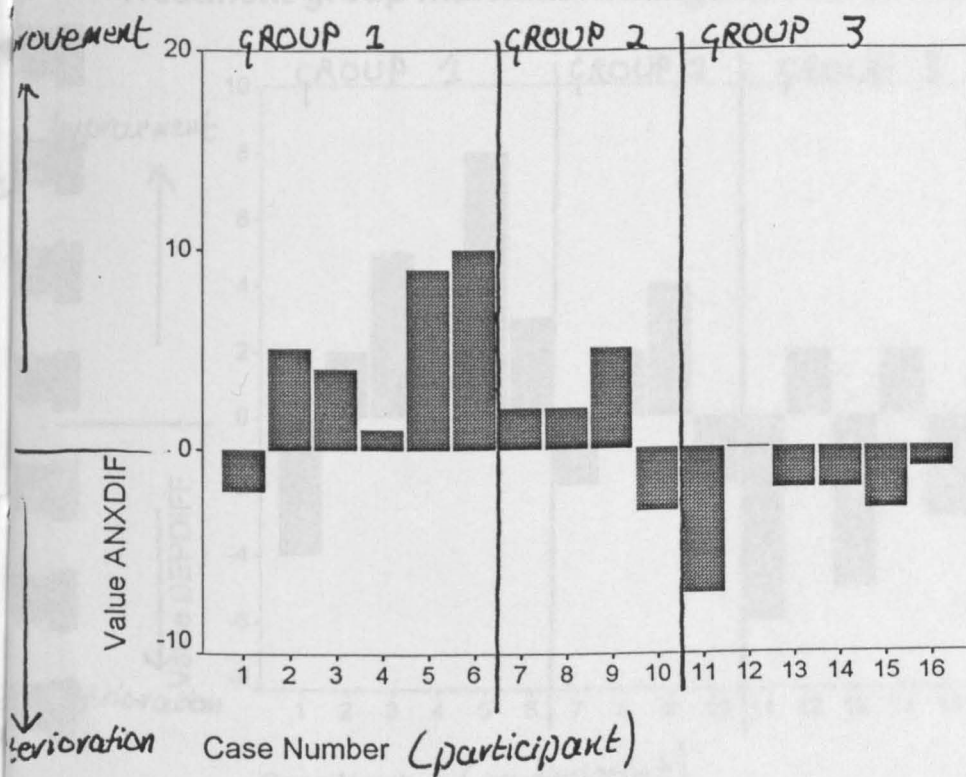
Treatment group individual change in scores: psoriasis-stress



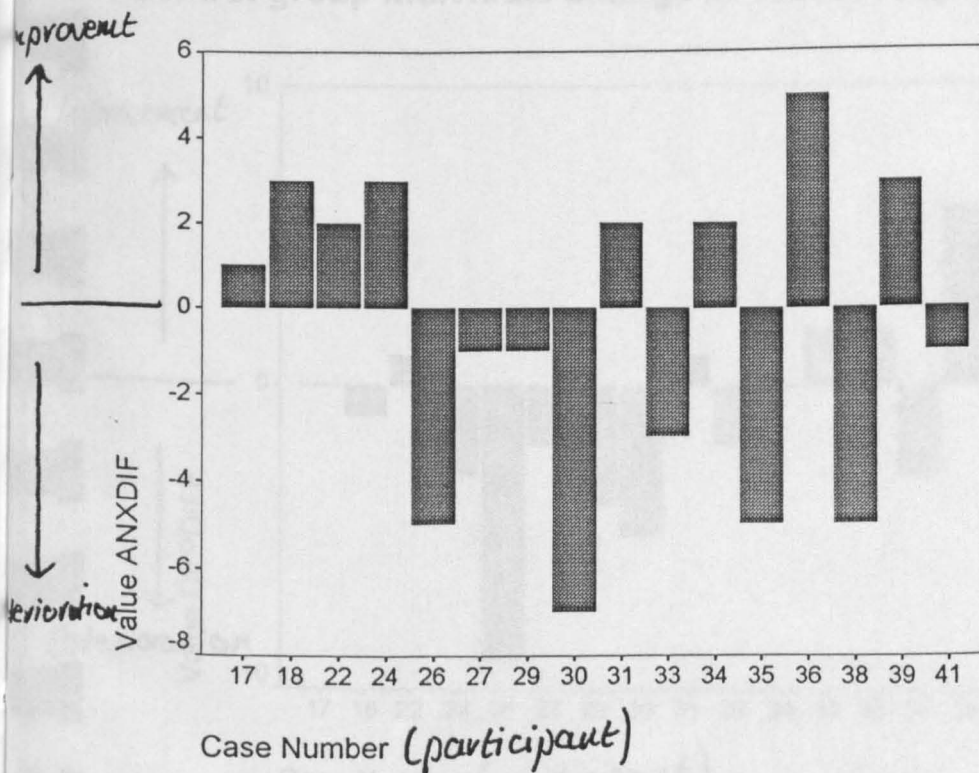
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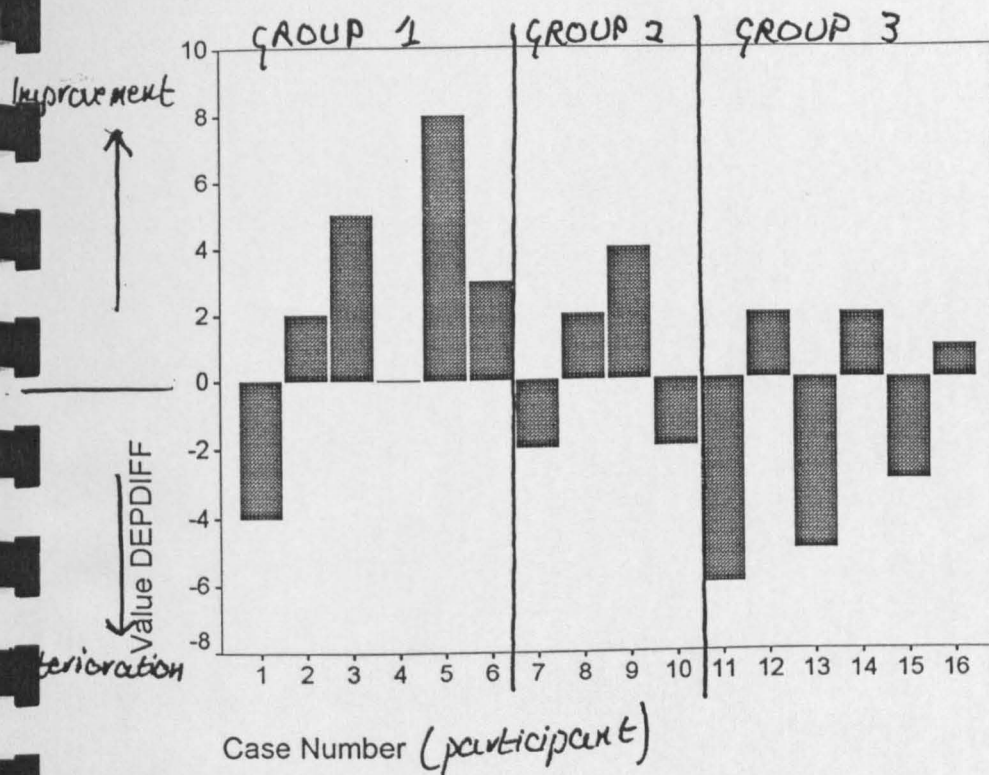
Treatment group individual change in scores: anxiety



Control group individual change in scores: anxiety



Treatment group individual change in scores: depression



Control group individual change in scores: depression

